

**An ethnographic study of critical care nurses' experiences
following the decision to withdraw life-sustaining treatment from
patients in a UK intensive care unit**

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Glossary of definitions, terms and abbreviations

Bands 5, 6, and 7 nurses – These are registered, qualified nurses who work in the NHS in the United Kingdom. Newly qualified nurses join the NHS as Band 5 nurses and as their career escalates they move higher to Band 6 and then Band 7. Salary scales and status are set in accordance with years of experience, additional qualifications and clinical expertise. The banding ranges from newly qualified nurses starting at Band 5 through to Band 7 which includes expert practitioners with several years of experience.

Comfort care refers to facilitating comfort for a patient where aggressive and life-sustaining treatments are no longer beneficial and cure is not possible. The focus of care changes from cure to comfort. Comfort care involves relieving suffering and maintaining patient comfort. In the event of withdrawing treatment, providing comfort care entails adequate pain management with sedation.

Critical care nurse – a qualified nurse who works in an intensive care unit.

EOLC – End-of-life care.

Futility – The ethical principle of futility is considered where a patient no longer responds to maximum life-sustaining treatment and further treatment is deemed futile; the decision to withdraw treatment is then considered and discussed.

ICU – Intensive care unit.

Level 3 category intensive care patients – Level 3 patients in the intensive care unit are categorised according to the Critical Care Minimum Dataset in the United Kingdom (UK) as a) patients requiring advanced respiratory support (e.g. invasive mechanical ventilator support via a trans-laryngeal tracheal tube or tracheostomy; bi-level positive airway pressure; continuous positive airway pressure or extracorporeal respiratory support) or b) patients receiving a minimum of two organs support (e.g.

basic and advanced respiratory, neurological, hepatic, renal, cardiovascular support) (ICS, 2009a).

All level 3 patients admitted to intensive care units present with physiological crises which necessitate invasive technological intervention and continuous haemodynamic monitoring to support the functioning of vital organs (ICS, 2009a)

NHS – National Health Service.

Patients – People who are critically ill being cared for in the intensive care unit and who require advanced technological support for vital organ dysfunction.

Palliative care refers to pain management.

Withdrawal of life-sustaining treatment – also referred to as withdrawal of treatment and treatment cessation throughout the thesis.

Abstract

The intensive care unit (ICU) embodies an environment of advanced technology and care, collaborative decision making and life-threatening emergencies. Critically ill patients are central to this unique milieu and culture, cared for by knowledgeable and skilful nurses who manage each patient's intensive care journey. Highly developed decision making skills become essential as life and death are often finely balanced. In the United Kingdom, once the decision to withdraw life-sustaining treatment has been made by the medical team, further decision making relevant to the actual withdrawal of treatment is conducted by nurses. The aim of this study was to explore critical care nurses' experiences following the decision to withdraw treatment from patients in a UK intensive care cultural setting.

An ethnographic lens of enquiry was the chosen methodology, and methods employed included 144 hours of observation and eight semi-structured interviews (using two vignettes) developed from the ICU experience. The research was conducted in a large 20 bed ICU in the North West of England. The participants were qualified nurses who met the main inclusion criteria of the study in that they had all experienced caring for a patient following the decision to withdraw treatment. Data analysis was undertaken using Ricoeur's analytical framework.

Three central themes emerged from the data analysis, namely: the decision to withdraw treatment; nurses' actions following the withdrawal of treatment decision; and shared experiences in the journey towards death. The findings suggested that nurses' created a private space for the dying patient and discovered a parallel journey towards death experienced by the patient, the nurse and the family. The nurse's adaptation from a curative focus of care to palliative care also emerged, where the desire was to offer positive and meaningful experiences for the family during this emotive phase of 'end-of-life care'.

Recommendations for clinical practice include the recognition of the value and benefits of formal and informal support for nurses during the patient's withdrawal of treatment and subsequent dying trajectory. Recognition of the importance of the intensive care environment as a whole for dying patients, their families and their care cannot be undervalued. In addition, given the palliative nature of care required of critical care nurses, a recommended of the inclusion of a palliative care specialist nurse in the multi-disciplinary team could enhance the patients' quality of end-of-life care.

Chapter 1: Background to the study

1.1 Introduction

This background chapter outlines how I located myself as a nurse researcher through my previous experiences and knowledge acquired by working in intensive care units (ICUs) in both southern and northern hemisphere countries. The life world of the ICU; the nurses' role during end-of-life care in the ICU; supporting the family during the dying trajectory; and withdrawing treatment from critically ill patients are all discussed. This is followed by the initial research aim of the study. A final section briefly outlines the structure of my thesis.

1.2 Locating the self in the research

The rationale for conducting this professional doctoral study arose from my previous experiences as a critical care nurse, together with my desire to give meaning to nurses' experiences during withdrawal of treatment from critically ill patients. Caring for level 3 patients necessitated a curative focus, but once the decision was made to withdraw treatment this focus shifted to comfort and end-of-life care. As a critical care nursing practice education facilitator, I was aware that nurses supported each other informally during the withdrawal of treatment, but that no formal debriefing was conducted. Furthermore, palliative care nurse specialist input and support was not considered appropriate in the intensive care setting during the patient's dying and death following withdrawal of treatment. In response to this experience I became aware that a gap in the nursing knowledge existed. My professional aspirations for self-development and the challenge of scholarly inquiry within this topic became additional drivers to study at a doctoral level. My intention was to add to the existing body of nursing knowledge relevant to withdrawing treatment in the critically ill patient profile within an ICU in the United Kingdom.

The trajectory of my nursing career spans many years as a critical care nurse and practice education facilitator, having previously worked in cardiology, cardio-thoracic, respiratory, neurosurgical, surgical and trauma intensive care units. Whilst conducting this study I was a senior lecturer at a University in the North West of England which included an academic link in practice role in an ICU at a NHS Foundation Trust hospital where the study was conducted. Critical care nurses are members of the intensive care multi-disciplinary team in the United Kingdom (UK), and their clinical input involves performing the withdrawal of life-sustaining therapies as passed down from the anaesthetic consultant. I believe that in this study critical care nurses played a pivotal role in caring for dying patients whilst supporting their families during treatment cessation.

Throughout my experiences as a critical care nurse, I became mindful of the frequency of treatment withdrawal in critically ill patients. This was especially evident in patients where no further treatment options were available and continuing treatment was deemed futile. Through seeking the meaning of the nurses' experiences within a nursing culture, it actually awakened my own previous experiences of withdrawing treatment and transformed me back to a time when I was a junior nurse working in a trauma ICU. One particular patient I remember withdrawing treatment from was a young male who had suffered a cerebral ventricular haemorrhage as a result of a diffuse axial brain injury sustained during a game of rugby. The brain stem tests revealed brain death and although organ donation was discussed, the patient's wife refused consent. The young man had recently got married and started a new life with his wife in their respective careers after both completed their university education. This experience where I withdrew treatment in a young man and supported his wife through his dying trajectory and subsequent death remains embedded in my memory. It was at the onset of my

intensive care career and my first experience of withdrawing treatment in a critically ill patient. I experienced a critical moment in my intensive care career as a result of this patient. It proved to be an extremely sad, thought-provoking dying trajectory following withdrawal of treatment in an intensive care environment. Throughout the following years of my intensive care experience, I subsequently withdrew treatment from many patients in various intensive care settings.

Another moment of epiphany occurred on a particular shift a few years later whilst working on an 8 bed ICU where three patients underwent withdrawal of treatment during a 7.5 hour shift. By the end of this shift, three patients had died and three families were in a state of bereavement. I experienced a deep sense of sadness for the patients and their families. Each patient's intensive care journey reminded me of a tapestry where each thread represented an event which was fashioned by an array of therapeutic rescue efforts to stabilise and maintain life at all costs. I believe that nurses become interwoven in their patient's tapestry of critical illness and subsequent intensive care journey.

At the beginning of each patient's intensive care journey family members offered and shared information relevant to the patient's individual characteristics and life prior to their critical illness. This information served to metaphorically clothe the patient's personality as they lay silent and motionless in a bed attached to life-supportive therapies. During this journey the nurses are immersed in the intensive caring of a critically ill patient whilst also supporting a family, which often induces in the nurse feelings and a sense of belonging directed towards the family. The withdrawal of treatment from these three critically ill patients proved to be a significant event which confirmed my intention to conduct research within this topic area. Throughout previous clinical experiences in ICUs, my professional stance was that patients' needs created a thirst for knowledge acquisition within the 'self'. I believed this

knowledge lent itself to insight, which in turn afforded a meaningful approach to best patient care, and improved patient outcomes and patient journey.

McGloin and McLeod (2010) state that the fluid nature of critical care nursing places nurses between the boundaries of life and death when they dealt with invasive advanced technology and the impact of this technology on the patient's body integrity and function. In my view as treatment is withdrawn, contemporary critical care nursing remains fused in a tapestry of curative and palliative care. Reflecting on my own previous experiences and having worked in different ICUs I realised that these experiences kindled an awareness of the personal, social and cultural contexts in which nurses lived and worked, and how this impacted on the ways nurses interpreted their intensive caring world. A relationship of mutual trust and respect usually developed between the nurse, the (albeit sedated) patient and the family during the patient's critical illness (McMillen, 2008). It is my belief that the privilege of caring for countless critically ill patients and supporting their families following the decision to withdraw treatment has added meaningful dimensions to my personal and professional life.

Nurses who live and work in an intensive care life world are influenced by cultural norms and values, which appear natural and contain cultural patterns of collective, shared experiences (Rytterstrom *et al.*, 2010). Evidence from the literature review revealed that there were a few ethnographic studies conducted with a specific focus on nurses' experiences of dying and death and the intensive care environment, but very few which focused specifically on nurses' actions and experiences of conducting the withdrawal of treatment and end-of-life care.

My methodological choice of ethnography stems from an anthropological perspective and exploration of the intensive care nursing culture and how the nurses managed the transition from cure to end-of-life comfort care and the patient's dying

trajectory following treatment cessation. Throughout the taught element of the doctorate, I recalled my exploration of different research methodologies and sought one that would best answer my research question. This aspect of methodological exploration formed an integral component of my personal development plan during this phase of my doctoral journey. After considering the various methodologies applicable to the qualitative paradigm, I chose ethnography as a lens of enquiry for its capacity to focus on the nurses' experiences within a specific intensive care setting. This choice was further ignited by my personal and professional fascination with the cultural aspects of nursing, and probably influenced by my socialisation plus many years of working in a complex and culturally diverse southern hemisphere country. In addition, Jane Seymour's (2001) seminal work, '*Critical Moments: Death and Dying in Intensive Care*' also proved to be a significant influence in the choice of topic. The chapter which addressed withdrawing medical treatment in intensive care and the problem of 'natural death' (Seymour, 2001, p. 91) highlighted significant aspects of the impact of withdrawal of treatment in ICUs.

What I realised was that like Seymour I had continuously reflected on critical moments during my years in clinical practice, making sense of and interpreting the world around me. Finley and Gough (2003) explained the notion of reflexivity as a defining feature of qualitative research where the researcher remains a central figure who actively constructs the collection, selection and interpretation of data. Arguably, adopting a reflexive approach during the research process guided me to situate myself and express my individuality as a researcher.

Opening up the process of withdrawing treatment and nurses' experiences for scrutiny seemed well suited to ethnography as well. Herbert (2000) stated that social life was not always observable and that meanings of objects and events were often revealed through practices, actions, cursory comments and facial expressions. This

view was supported by Harper and La Fontaine (2009) who suggested that what we did in our everyday working lives and the meanings behind our actions were implicit and tacit and, as such, not always open to immediate discovery or interpretation. Etherington (2004) further urged researchers to be aware of their own positions and interests in order to explicitly situate themselves within their research. My intention was that using an ethnographic lens of discovery would facilitate my role as a researcher, allowing me to become immersed into the cultural world and take an exploratory inward gaze into how nurses' withdrew treatment from patients.

Holland (1998, p. 1462) believes ethnography affords value to nursing as:

... it addresses both the means of developing a research culture whilst also being a tool to explore the culture of nursing itself.

I anticipated that an ethnographic enquiry would capture, interpret, and explain the way in which nurses in a large ICU lived, experienced and made sense of their lives, their world and the society they belonged to (Bentz and Shapiro, 1998). This enquiry would necessitate observing their behaviour, exploring their moral and social rules and their ideas, in order to understand how the nurses managed withdrawing treatment and experienced the patients' dying trajectory. The intention was that ethnography would illuminate and aid the production of knowledge, in a field where we understand relatively little about the mechanisms of delivering quality end-of-life care, or about making critical decisions about life and death in a clinical discipline where mortality remains high.

1.3 Life world of the intensive care unit

Seymour (2001) suggested that, globally, death in an ICU is characteristic of a complex and contradictory milieu. The intensive care environment represents the modern preoccupation with the mastery of disease entities, the eradication of untimely death, the prolongation of life and attempts to enhance dignified end-of-life

care (Seymour, 2001). There has been growing concern amongst healthcare professionals and the general public alike that excessive technological and expensive invasive treatment used in the ICU to provide potentially life-saving therapy may in fact unnecessarily prolong patients' suffering at the end of their lives (Curtis and Rubenfeld, 2001). There appears to be a trend where an increasing number of patients within ICUs are supported and cared for although their prognosis is poor (McGloin and McLeod, 2010). The ICU therefore represents a place where critically ill patients receive life-sustaining therapies in an attempt to reverse the illness; but despite these goals of intensive caring, the number of patients dying in ICUs remains significant, with figures ranging from 1 in 5 to as high as 1 in 3 patients (Wunsch, *et al.*, 2005; Intensive Care National Audit and Research Centre [ICNARC], 2010). In an event where a patient no longer responds to maximum supportive treatment, the decision to withdraw treatment is based on the ethical principle of futility, where further treatment is deemed futile. Beneficence and non-maleficence, 'to do good and not harm' to patients, remain important ethical principles within clinical practice. However, when patients no longer respond to maximum life-sustaining treatment, then the ethical decision to withdraw treatment arises.

Both social and technological systems exist in the intensive care specialty. Social systems comprise expert and knowledgeable healthcare personnel who work in the ICU and share similar beliefs, rituals and group norms, and encounter similar hierarchies and political forces (Daly, 2001). These specially trained medical and nursing personnel work together as a team in a world of challenging medical practices and emergencies. Advanced technological equipment and techniques, together with specific procedures and protocols, comprise the technological systems (Daly, 2001). Advances in critical care nursing expertise, advanced technology and treatment options may have influenced the increased number of patients admitted to

the ICU who receive life-sustaining treatment despite having a poor prognosis and being in a futile situation (British Medical Association [BMA], 2007; Stroud, 2002). This in turn influenced the incidence of withdrawal of treatment in ICUs, as opposed to death despite full active management (BMA, 2007; Stroud, 2002). As treatment is withdrawn, the patient's management continues in a compassionate and caring fashion with sedative and analgesic therapy maintained for comfort and pain relief, but not at dosages that may intentionally hasten death. Treatments aimed at primarily supporting organ function but which may prolong death are withdrawn; for instance, cardiovascular vasopressor therapies, renal filtration support, terminal respiratory weaning or terminal respiratory extubation. As interventions to improve end-of-life care and decision making are developed, it is important to understand how they may interact with the intensive care culture, formal and informal rules, the meaning and uses of technology, roles and relationships amongst critical care staff, and rituals such as intensive care rounds (Baggs *et al.*, 2007). The British Medical Association's (2007) guidelines on withdrawing treatment stress the need for a consensus in decision making and highlight the importance of good communication, both in the decision making process and the actual withdrawing of treatment (McLeod, 2014).

Vincent *et al.*'s (2004) findings support this stance that in the UK, end-of-life decisions are made by the whole ICU team and that nurses play a valuable role in the decision making process (Puntillo and McAdam, 2006). Any patient who experiences a medical crisis is admitted to an ICU immediately unless circumstances dictate otherwise. However, many patients deteriorate despite maximum therapies and fail to survive (Efsthathiou and Clifford, 2011). Mortality rates in adult ICUs in the UK are 17.1% of all admissions (ICNARC, 2010), indicating that caring for a dying patient is an integral and frequent component of critical care nursing.

Pattison (2011) and Truog *et al.* (2008) have written extensively about the symbolic nature of the ICU as a curative environment where therapeutic trial of treatment with the goal of supporting and treating reversible causes of critical illness is practised. However, the occurrence of death remains common in the intensive care setting due to patients' severity of critical illness prior to intensive care admission (Curtis & Patrick, 2001). The ICNARC data indicate that over 15,000 patients in the UK died in ICUs for the year 2008-2009 (Pattison, 2011; ICNARC, 2010, 2011). Level 3 intensive care patients were categorised according to the Critical Care Minimum Dataset in the UK as patients who required advanced respiratory support or patients who received a minimum of two organ support [ICS, 2009a]. These patients presented with a primary pathophysiological crisis which usually necessitated invasive technological interventions, haemodynamic monitoring and advanced nursing to support vital organ functions. The focus of nursing care in the UK was on assessing patients' physiological status, modes of ventilation, haemodynamic monitoring and curative care because for the majority of critically ill patients this was their fundamental need (Coombs *et al.*, 2010). However, for the sub-set of patients who did not survive ICU, palliative comfort care was indicated with an emphasis on a pain free and dignified death.

Life-supportive measures aim to enhance quality of care and include features of the environment, such as supervisory techniques, role descriptions and the nature of work within the ICU. The availability of advanced care and advanced supportive therapies in UK ICUs means critically ill patients are eligible to access these resources during their critical illness. A medical director, anaesthetic consultants, anaesthetic registrars, senior and junior nurses, healthcare assistants, cleaners, physiotherapists and pharmacists usually comprise the intensive care multi-disciplinary team. Each team member remains accountable for their own set of roles

and responsibilities. Every patient's progress and haemodynamic status is assessed during the morning intensive care round, and treatment regime's for the next twenty-four hours are planned.

Intensive care clinical practice has evolved towards a more active role for doctors and nurses in managing the deaths of patients in the ICU, according to Luce and Prendergast (2001). Changes in roles are reflected in the increased incidence of withdrawing life-sustaining support and use of advance directives (Morgan, 2008). In part this change, I would argue, has been influenced by a shift in professional and public attitudes regarding treatment that is unlikely to benefit patients, alongside the success of advanced biotechnology used therapeutically in the ICU to sustain homeostasis and bodily organ functions. However, Halcomb *et al.* (2004) suggested this biotechnology has created additional ethical and moral dilemmas as it could not always cure disease entities and often merely prolonged the patient's inevitable dying. A tension sometimes existed between maintaining life and relieving suffering associated with inappropriate prolongation of life due to the nature of intensive care clinical practice (McMillen, 2007). Since the advent of the intensive care specialty in the early 1960s, the need to address complex issues arising in clinical practice has been prevalent (Seymour, 2001). The contemporary issue of treatment cessation persists. The 'uncertain/unknown' dying trajectory identified by Glaser and Strauss (1965) as the least likely route to death in the 1960s not only posed a problem for doctors and nurses caring for critically ill patients following withdrawal of treatment (Seymour, 2001). It also influenced wider societal dilemmas regarding end-of-life decision making and providing a 'good' death (Seymour, 2001). Although medical and nursing personnel in ICUs often viewed death as an enemy from a curative, rescue focus of care (Pattison, 2004), Kirchhoff *et al.* (2000) postulated that most Americans feared how they would die, rather than death itself. The modern medical

view perceived individual patients as no more than carriers of multiple disease entities, according to Seale (1998).

In '*Limits to Medicine*', Illich (1976, p. 106) states:

[[I]ntensive care is but a medical priesthood struggling against death.

Despite Illich (1976) suggesting that one cannot die a good death with technology, Pattison (2004) argued that humanistic care, despite medical technology, can be brought about by human agency in critical care and expert nursing care that reconciles technology and dying. I believe that the nurses' use of the 'therapeutic self' affords a fusion between technological and bodily dying in that it is a powerful influence in promoting a good death in the intensive care environment. The authors Seymour (2001) and Pattison (2004) contend that a critically ill patient can die a good death whilst in the intensive care environment as long as the patient's treatment involves dignity and holistic care. However, creating a beneficial environment for dying to occur in a busy ICU is always going to be a challenging reality. In an attempt to create this environment for dying, nurses' roles as coordinators of end-of-life care have evolved into advocates, information brokers and comforters during treatment withdrawal.

Within the intensive care milieu, death has almost been tamed by an array of medical, surgical, technological and pharmaceutical interventions which served to 'buy time' for patients with life threatening illnesses (Earle *et al.*, 2013). Advanced technology, skilled personnel, defibrillators, ventilators, cardiac monitoring equipment, and drugs to save lives and avert death enfolded each patient's bed space in the ICU (Hockey *et al.*, 2010).

From a cultural perspective, Miller *et al.* (2001) suggested that death was viewed through the lens of biomedical knowledge due to medical advances changing how, when, and where people die. In the past, death was a routine part of a person's life: the presence of death and its associated rituals went unchanged for centuries, as

friends, family and the community gathered to share the experience and create meaningful respect in the recognition of a dying person. However, medical science appears to have replaced religion and nature in providing a conceptual framework for understanding dying and death where it was not viewed as a natural life event, but rather a disease to be treated and conquered (Miller *et al.*, 2001).

ICUs housed patients with chronic illnesses who experienced numerous exacerbations, only to be rescued from the brink of death by sophisticated technological interventions (Miller *et al.*, 2001). This unpredictable nature of chronic illness disguised the dying trajectory, creating what Callahan (1993) referred to as the vanishing line between life and death, where death was no longer experienced as a natural outcome, but rather as an inadequately treated disease, a failure of modern medicine. From my own previous clinical experience it was evident that this viewpoint was often adopted by doctors and nurses alike when the decision to withdraw treatment was sanctioned. Seymour (2001) argued that the uncertain death and unknown time question remained a salient concern within the advanced technological rescue focus of intensive care clinical practice. Managing life threatening illnesses in ICU was part of the curative aspect of care, and the expectation was that the patient would leave the ICU rescued and alive. However, when this was not possible despite all medical efforts and advanced technological interventions, nurses were filled with a sense of guilt.

To the outsider, the intensive care unit appeared to be a secluded and strange life world inhabited by silent, sedated patients attached to an array of pulsating invasive machines and monitors, and a clinical setting which could be mistaken for a scene from a science fiction film. The ICU represented a restricted area yet it was paradoxically a public space, where there was a constant flow of visitors, doctors, nurses, radiographers, physiotherapists and other hospital personnel. In my view, it

also appeared to be an exposed area, where patients' bodies were exposed to the flow of visitors and personnel who passed through the ICU. In an ethnographic study which explored nursing culture in an ICU in the UK, the findings suggested an uncertainty existed surrounding the boundary between life and death, which was complicated by the fact that the life of a patient in ICU required invasive technological support (Philpin, 2006). Additionally, there appeared to be a violation of bodily boundaries where airways, major blood vessels and the very essence of patients' lives were opened up and made accessible to the gaze of those caring for them (Philpin, 2006). Hence, a tension exists between notions of public and private space. Advanced technological apparatus and invasive flashing lights, buzzing and beeping monitors, gurgling suction machines and whooshing ventilators surrounded each patient's bed space. Within this intensive milieu, personnel rush around busily to attend to extremely ill patients, and deal with medical emergencies and other life-threatening crises. Critically ill patients lie silent, attached to invasive monitoring devices which emit abhorrent, nonhuman noises. This is the surreal life world of the nurses who work in the ICU, where death appears often but dying is constant.

1.4 Nurses' roles during end-of-life care in the intensive care unit

In the United Kingdom a curative focus of nursing care co-exists alongside the palliative component of comfort care during the patient's dying trajectory following withdrawal of treatment (McMillen, 2007). Nurses care for dying patients and support families during the fraught and fragile event of treatment withdrawal (Rocker *et al.*, 2010). I believe nurses have attained the appropriate knowledge to interpret and manage the clinical manifestations of a multitude of disease entities and effectively orchestrate the advanced technology to manage life-sustaining therapies in critically ill patients. However, nurses have acknowledged a shortfall in their education and

training pertinent to palliative and bereavement care, despite the inclusion of dying and death subject content in university curricula (Morgan, 2008). Critical care nurse training and experience relevant to withdrawing treatment both in the UK and America predominantly occurred in clinical practice because almost 25% of the nurse's work involved non-surviving intensive care patients (Wunsch *et al.*, 2005; Beckstrand *et al.*, 2006; Morgan, 2008).

Auger (2007) and Seymour (2001) described an 'unnatural' death as one where the patient was attached to life-sustaining equipment in a hospital environment, for instance the ICU, and being cared for by strangers. I would argue that nurses provided valuable input towards the planning and implementation of end-of-life care, which is supported by Shorter and Stayt (2009) who described the notion that nurses perceived the death of a patient as less traumatic if the patient died a good death. Pattison (2011) suggested that a good death following withdrawal of treatment in the ICU was perceived as uncomplicated dying where the patient was pain free and comfortable. I recall from previous clinical experience that nurses would prefer to keep the dying patient attached to the ventilator and with all invasive lines left *in situ*, especially the sedative and analgesic infusion lines, because this was how the family had become accustomed to seeing the patient. In this way the dying patient's airway was maintained so noisy dying from accumulated bronchial secretions in the airway was avoided, the patient was kept pain free and sedated, and the dying trajectory appeared uncomplicated. I would agree with Halcomb *et al.* (2004) who suggested that to die a good death, a pain free and dignified death should be perceived as a clinical success. Nurses continually face the daily clinical and emotional challenges of redirecting their efforts from cure to comfort in the face of death by the provision of dignified end-of-life care. The research findings of Halcomb *et al.* (2004), Puntillo *et al.* (2001) and Kirchhoff *et al.* (2000) all bear a common theme: a pain free,

comfortable patient afforded dignity during the dying trajectory at end-of-life. In addition, good end-of-life care included effective communication between the intensive care staff and the patient's family in an attempt to assist them to accept and cope with the reality of the patient's prognosis.

Pattison (2011) believed that nurses should be protagonists in contributing towards end-of-life care decision making, planning and implementation due to their close proximity to and contact with patients and their families. I would concur with Pattison's (2011) viewpoint. Throughout my previous clinical experiences, it was evident that a climate of caring and support usually developed between the often silent, sedated patient, the nurse and family during the patient's intensive care journey, which was reinforced during dying and death. Levy (2001) believed nurses should deal with uncertainty in a confident and reasoned manner, because making a personal relationship with death and the process of dying depended on the ability of the nurse to deal with uncertainty in the ICU. In addition, a fundamental quality of a good end-of-life caregiver was being comfortable with the process of dying (Levy, 2001).

However, in reality, critical care nurses deliver care for both living and dying patients in the ICU. Pattison (2004) explained that there should be no division between critical care and palliative care within end-of-life in the ICU, and suggested that end-of-life may be enhanced by the fusion of these divisions. Furthermore, Pattison (2004) raised the issue that nurses carried the responsibility for implementing decisions where multiple technological interventions were exchanged for palliative care options during the practice of withdrawing treatment. Seymour (2001) described how dying and death in the ICU were not merely technical matters which involved issues of cost and statistical significance: when patient recovery was the least likely outcome, withdrawing treatment necessitated moral and ethical

consideration. I recall from my own personal experience a conversation with a consultant anaesthetist who viewed the challenge to sustain life as rewarding and thought that when curative care changed to palliative care, this reward no longer existed. What this consultant further disclosed was how in making the decision to withdraw treatment he felt that he had somehow 'failed to rescue and save the patient'. Interestingly, nursing colleagues also shared similar feelings of failure and loss of control of a situation during withdrawal of treatment. Death was to be avoided at all costs in a curative, rescue culture of care. This perspective was echoed by Seale who viewed death as:

...no more than an extreme example of disease (Seale, 1998, p. 77).

During withdrawal of treatment, nurses faced a dichotomy situation where they intellectually rationalised the decision to forgo treatment of the critically ill patient as a palliative measure to prevent further burden from unwarranted treatment (Rocker *et al.*, 2010). However having rescued the patient initially from possible death, it was difficult to relinquish a controlled situation as this often induced a sense of failure. According to Morgan (2008), nurses' cognitive abilities and skills associated with curative care were exchanged for the emotional tension and comfort behaviour of palliative care. During the patient's dying, nursing care focused on patient comfort and dignity. An element of uncertainty existed with regard to the time from withdrawal to death, and this unknown time placed an enormous challenge and additional demands on the nurse to make a difference for both the dying patient and the bereaving family (Neuberger, 2003).

In the UK, different tensions existed regarding end-of-life issues in the ICU. These tensions encompassed issues relevant to a different population base, different cultures and different values held, which contributed towards the challenges in critical care to achieve end-of-life consensus (Coombs *et al.*, 2010). Deciding to withdraw treatment occurred in patients who were dependent on the technology, courtesy of

the life-support machines, but with arguably no hope of recovery (Jones & FitzGerald, 1998). The worldwide fundamental aims of intensive care were to maintain life, relieve suffering and reverse the illness, which exemplified the aspirations for a curative focus of care. Death, however, was a constant and stark reality which dictated a different focus of care (Halcomb *et al.*, 2004).

1.5 Supporting the patient's family during the patient's dying trajectory

Caring for the dying patient was synonymous with caring for the patient's family. As the various therapies were withdrawn during the dying trajectory, the nurse caring for the patient redirected this care to the family. Nurses adopted an empathetic and nurturing approach towards the family during the patient's dying and death. Often the mere presence of the nurse or quietly being there for the family and with the dying patient was sufficient. The family required clear, timely and consistent information regarding withdrawal of treatment and the patient's impending dying trajectory. Additionally, the family needed reassurance that the dying patient was in fact pain free and comfortable, and that the patient's wishes had been respected, in order to find meaning in the death of a loved one (Rocker *et al.*, 2010). Suffering a critical illness in an intensive care unit was more than just a physical experience for the patient, their family and the nurse caring for the patient. The essence of the caring relationship which usually developed during the critical illness embodied the human, social and spiritual dimensions of holistic care. Families may find themselves inclined towards spirituality during a health crisis such as withdrawal of treatment to enable them to make sense of and seek meaning from this life event (Hexam *et al.*, 2011; Timmons and McSherry, 2012). The concept of spirituality encompasses many definitions and interpretations; however, it may be described as an umbrella term with many interwoven attributes (Timmons and McSherry, 2012). In a sense it

embodies an individual's unique experience of existence within the realms of seeking meaning in life and exploring the reality of the environment and universe (Timmons and McSherry, 2012). The opportunity for cultural and spiritual support was offered to every patient prior to withdrawal of treatment. The concept of spirituality and delivery of spiritual care are recognised as fundamental aspects of the nurse's role (McSherry & Jamieson, 2013). Families of dying patients experience emotional distress and anxiety, accompanied by a tendency towards denial of death and difficulties in understanding medical information (Rocker *et al.*, 2010). Effective and informative communication necessitated sharing the decision to withdraw treatment with the family at a private meeting in open, honest discourse. Lautrette *et al.*'s (2007) research draws attention to the importance of informative end-of-life meetings with the patient's family in order to discuss the decision to withdraw treatment from the critically ill patient. In Lautrette *et al.*'s (2007) study, the researchers used a proactive communication strategy that included taking the time to listen to the family's questions and concerns. One of the findings of this quantitative study suggested that by adopting a communication and listening strategy the burden of bereavement may have been minimised (Lautrette *et al.*, 2007). The issue of talking less and listening more when breaking news to the family during end-of-life meetings was highlighted in Seymour's (2001) seminal work. It was Seymour (2001) who proposed that clinicians and nurses should ideally provide timely clinical prognostic information in order to support the patient and their family with regards to withdrawing treatment in the ICU. Arguably, this transition from individual responsibility to patient-focused consensus often permits the family to understand, perhaps reluctantly and with great sadness, that intensive caring may involve letting go of life-sustaining interventions.

Improving the quality of end-of-life care in the ICU remains an issue of paramount interest because it is a place where mortality remains high (Seymour, 2001). It is a

common location where medical and nursing staff, families, and patients make the transition from attempting to cure disease entities and prolong life to providing comfort and allowing dignified dying and death (Curtis & Rubenfeld, 2001). Patients who are hospitalised during acute illness are often at risk of requiring multiple organ support in the days and hours immediately before death (Seymour, 2001). Caring for the dying patient and supporting the family through the dying phase until death is a life event which the nurse cannot afford to get wrong.

1.6 Withdrawing treatment from critically ill patients

The intensive care patient is usually unaware of their own dying as a result of their critical illness, together with an induced sedative and analgesic state which is administered to optimise comfort and alleviate pain during the dying trajectory (Seymour, 2001). A dichotomy may exist between the action to allow death to unfold 'naturally', which attributes death to the patient's body, and to almost hastening death through withdrawal of treatment, which attributes death to the nursing practice of withdrawing treatment. Once organ supportive therapies have been withdrawn, the patient's haemodynamic status deteriorated and in this poor output state the dying trajectory soon became established. The process of withdrawing treatment was a strategic practice where advanced life-sustaining technology was slowly withdrawn to almost mimic the 'natural' decline of death in accordance with prescriptive norms concerning the proper course of natural dying (Mohammed and Peter, 2009).

Medical technology therefore becomes constitutive of the natural to the extent that it frames and determines dying and death by slowly unfolding, and in this way offering a space for the family to start grieving and the presentation of a less dramatic death (Mohammed and Peter, 2009). By removing the life-sustaining technology from the patient during treatment withdrawal, the patient's dying may be perceived

symbolically as a process of being given permission to die, which is socially more acceptable and therefore shifts the responsibility of death away from nurses who operationalise the actual withdrawal (Mohammed and Peter, 2009). In modern society, death is not always a popular discussion theme in our death-denying culture, yet it remains a pivotal aspect of our social life (Seale, 1998).

Bauman (1992) argued that in the modern hospital setting death was often viewed as a result of a host of preventable diseases, which symbolically suggested the notion that death may be controllable. In the intensive care environment, this locus of control was especially apt and deeply embedded in the curative focus of care, even during the patient's dying trajectory. The doctor made the final decision to withdraw treatment, but in the UK nurses operationalise the actual withdrawal. However, despite the certainty of death following withdrawal of treatment, the time from withdrawal to death remains uncertain. Where a patient no longer responded to maximum life-sustaining treatment and further treatment was deemed futile, the decision to withdraw treatment was considered and initiated.

Luce and Prendergast (2001) described the legal and economic drivers which influenced intensive care clinical practice and reinforced a trend towards limitation of ineffective treatments in the United States. Organisational costs and the laws of the country still impact on current clinical practice and the nature of death in the ICU. In the UK, the legalities relevant to withdrawal of treatment in critically ill patients in the ICU and intensive care bed resources influenced the limitation of ineffective therapies. Historically, critically ill patients died despite maximum technological support, whereas patients are more likely to die in the future following withdrawal of treatment (Luce and Prendergast, 2001). This aspect of dying following withdrawing treatment remains especially apt in the UK for several reasons. Firstly, no inclusion or exclusion criteria exist for admitting patients to the ICU within the NHS, so all patients

are afforded intensive care by virtue that the advanced technology is available. Secondly, often patients with a poor prognosis are admitted to the ICU for life-sustaining treatment where the outcome remains unfavourable.

Mercer *et al.* (1998) conducted an audit of 100 patients in a general ICU in the UK and reported that a 72.6% mortality rate following withdrawal of treatment was evident. The results of the audit indicated the impact of economic and ethical drivers on clinical practice and the changing nature of death in the ICU, especially the legal issues relevant to withdrawing treatment in patients and the availability of ICU bed resources. These drivers included the cost of intensive care treatment and the ethical considerations pertinent to withdrawing treatment from critically ill patients. The intensive care team need to find an acceptable path through the legal and moral dilemmas of treatment cessation in critically ill patients who do not respond to maximum therapies, and for whom continued treatment is deemed futile (McGloin and McLeod, 2010).

In clinical practice each patient's individual case and response to therapy is reviewed and discussed before the decision to withdraw treatment was made by the consultant. Beneficence towards the patient outweighs the need to continue ineffective maximum therapy which merely prolongs the inevitable and the patient's suffering. Glover (1990) believes that when a patient has an illness from which there is no hope of recovering, it is often suggested that medical intervention which goes beyond easing the pain or distress is not saving life but prolonging the act of dying. The increased power of medical techniques and advanced technology often keep critically ill patients alive much longer. In a sense, these complex situations often transform the moral question of euthanasia, according to Glover (1990).

UK law forbids active euthanasia, but passive euthanasia is outlawed only when a positive duty to save a patient's life exists (Harris, 1991). Withdrawing treatment on

clinical grounds should only occur in the event when treatment will not benefit the patient or the expected benefits are outweighed by the burdens of treatment (McGloin and McLeod, 2010). The principle of double effect exists within healthcare.

Harris (1991) describes the principle of double effect which relates to direct and side effects in healthcare:

...where you may not aim at someone's death, causing it does not necessarily incur guilt - it can be that there are necessities which in the circumstances are great enough or there are legitimate purposes in hand of such a kind to provide a valid excuse for risking or accepting that you cause death – [but] without such excuse foreseeable killing is either murder or manslaughter. (Harris, 1991,p.43).

Analgesia is administered as a direct effect to maintain comfort and manage pain in the dying patient following withdrawal of treatment. However, a side effect of this medication is respiratory depression with cessation of breathing which may hasten death. In a similar vein, withdrawing life-sustaining treatment in critically ill patients will lead to an imbalance in homeostasis and organ support, and the patient's biological systems will cease to function with the resultant loss of life. Withholding treatment is associated with withdrawal of treatment, and involves a process through which various medical interventions are not administered to a patient due to the expectation that the patient will die from their underlying illness. To differentiate euthanasia from withdrawal of or withholding treatment, Emanuel (1994) is of the opinion that euthanasia may be viewed as administering medication or performing other interventions with the intention of causing a patient's death. I believe that withdrawing treatment from a critically ill patient who no longer responds to maximum therapies is a humanitarian act of compassion.

Withdrawing treatment from critically ill patients may be viewed as a form of euthanasia in different countries and cultures. However, the Intensive Care Society (2009) stipulates that euthanasia is illegal in the UK and plays no part in the withdrawal of life-sustaining treatment from critically ill patients.

1.7 Research aim

The broad aim of this thesis was to explore critical care nurses' experiences following the decision to withdraw life-sustaining treatment from patients in a UK ICU. The final decision to withdraw treatment rested with the intensive care consultant anaesthetist, and the responsibility for carrying out this decision was transferred to the nurse caring for the patient. This then became a nurse-led practice.

My intention was not to generate theory but rather a cultural exploration of my participant's experiences within an ICU, locating dying and death within this specific clinical setting. The focus of this research was the critical care nurses who I believed played a key role during the decision making process, and especially the management of the patient during the dying trajectory and death.

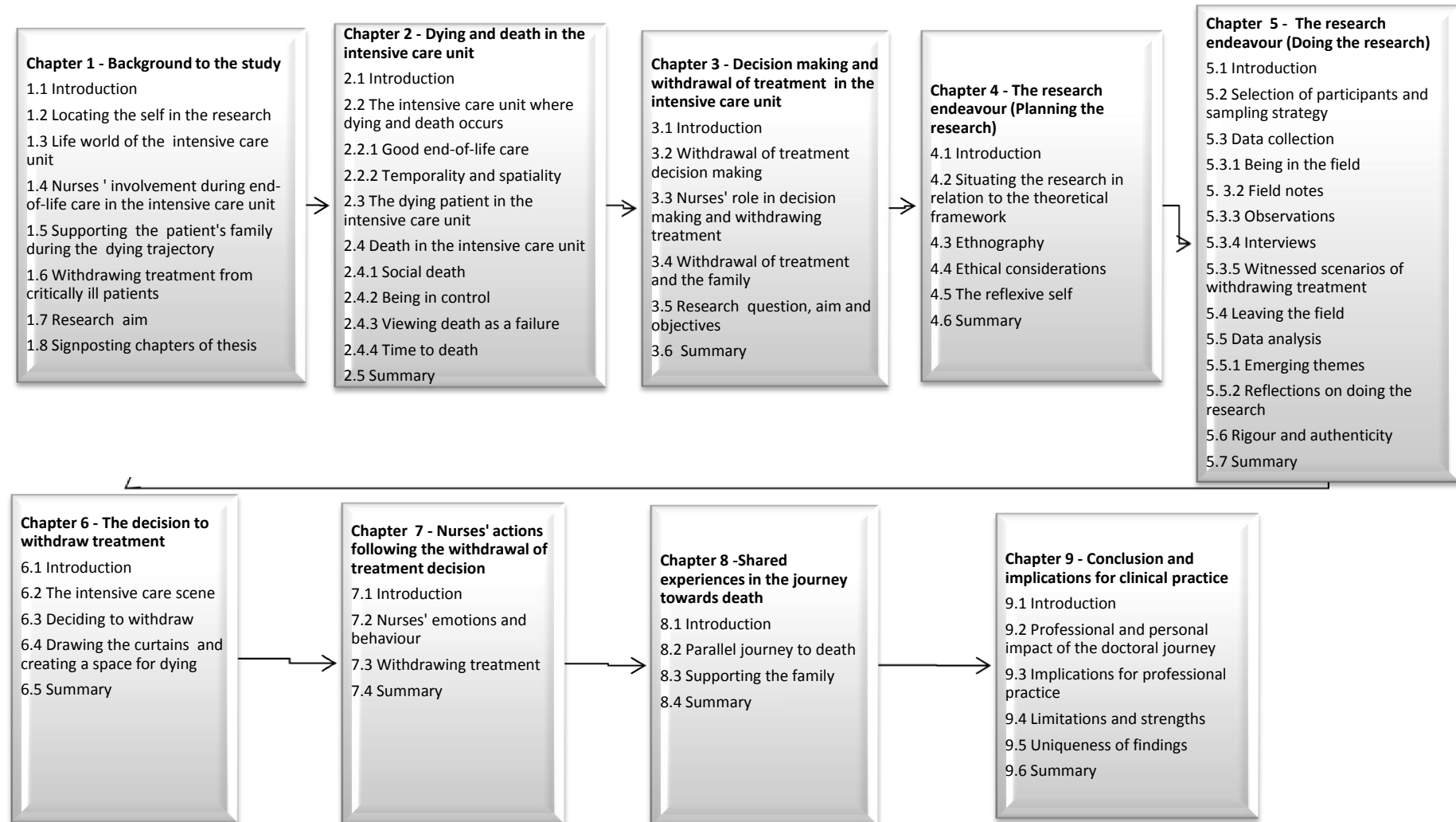
1.8 Signposting chapters of thesis

This thesis is a part fulfilment for a professional doctorate and offers the reader a share in the journey of discovery. This chapter has discussed the background to the study with the inclusion of the aim; how I locate the self as a researcher; nurses as protagonists during end-of-life care; and deciding to withdraw treatment and withdrawing treatment from critically ill patients. Chapter 2 and chapter 3 provide an overview of the literature pertinent to withdrawing treatment, nurses' experiences of withdrawing treatment in the ICU, and dying and death in the intensive care unit. Chapter 4 discusses planning the research including the methodology, theoretical framework, ethical considerations and the reflexive self. Chapter 5 includes undertaking the study including aspects relevant to participants, data collection and analysis, reflections on transcribing, rigour and authenticity. Chapters 6, 7 and 8 discuss the findings from the study which encompass the central themes which

emerged from the data analysis. The study's conclusions and recommendations for professional practice are discussed in chapter 9.

A synopsis of the chapters in the thesis is presented overleaf (Figure 1).

Figure 1: Chapter synopsis



Chapter 2: Dying and death in the intensive care unit

2.1 Introduction

Chapter 2 and chapter 3 include a discussion of the central themes which emerged from the literature search and review. Chapter 2 incorporates the intensive care unit where dying and death occurs; the dying patient in the ICU; and death in the ICU. Chapter 3 encompasses deciding to withdraw treatment; nurses' role in decision making and withdrawing treatment; and withdrawal of treatment and the family.

2.1.1 Search strategy

The literature search was conducted in an attempt to identify published material pertinent to nurses' experiences of withdrawing treatment and care of the dying patient in the adult ICU. Relevant research papers aligned to the aim and objectives of this study were retrieved. The literature review was based on the electronic databases CINAHL, Medline, Embase, PsycINFO and the Ethos website, including citation tracking and hand searching of relevant journals namely, International Nursing in Critical Care, Intensive and Critical Care Nursing, British Association of Critical Care Nurses, British Medical Journal, American Journal of Critical Care, International Journal of Nursing Studies, Journal of Clinical Nursing, Journal of Advanced Nursing, British Journal of Neuroscience Nursing, International Journal of Palliative Care and Journal of Intensive Care Medicine. To complement the quality and range of literature within the search, relevant non-published literature, published policy documents and knowledge from experts in the field were also collated and read.

MeSH search terms separated or linked concepts of 'intensive care nurses', 'critical care nurses', 'dying and death in ICU', 'end of life care', 'curative care', 'intensive care unit', 'intensive care practice', 'decision-making process' and

'withdrawal of treatment'. References and bibliographies at the end of articles were scanned and a few were obtained to widen the search retrieval. The search yielded 3,305 potential articles. Reading the abstracts condensed the initial selection down to 195. Omitting the search term 'end of life' with the inclusion of 'adult', 'withdrawal of treatment practice' refined the search down to 48 significant publications. Abstracts were read, and all the relevant articles that on initial inspection appeared to fulfill part or all of the inclusion criteria were retrieved. The full text of all articles which appeared pertinent to the topic was obtained. The search strategy included the retrieval and validation of the relevant literature within the confines of inclusion and exclusion criteria.

Inclusion criteria included:

- documents in English,
- documents with abstracts,
- peer reviewed articles,
- 1990 to present

Exclusion criteria included:

- children,
- letters,
- Languages other than English.

The review and appraisal of current research evidence explored the social and cultural context of ICUs globally, with a particular focus on critical care nurses' experiences following the decision to withdraw treatment from critically ill patients.

The retrieved articles were based on studies conducted in the following countries: the UK, Netherlands, Australia, Israel, the United States of America, Norway,

Sweden, Canada, South Africa and Thailand. However, the British research articles by Seymour (2001), Philpin (2007); Coombs *et al.* (2010, 2011); Pattison (2006, 2011) and McMillen (2008) were central to the literature review as these articles were pertinent to decision making at end-of-life, critical care nurses and intensive care units in the UK. Books written by experts in the field within the disciplines of anthropology, sociology, and critical care practice applicable to dying and death within the intensive care setting were included in the literature review. On the one hand there was a plethora of publications relevant to general issues of end-of-life care in the intensive care unit setting within the current literature. However, a gap in the literature was apparent with regard to how nurses managed the withdrawal of treatment and nurses' experiences during the patient's dying trajectory. Withdrawing treatment from critically ill patients in the UK involves a nurse-led practice because research evidence suggests critical care nurses are more autonomous in their clinical practice compared to their European counterparts (Latour *et al.*, 2009).

I employed Benton and Cormack's (2000) framework for critiquing the relevant articles (Appendix A) as it was an appropriate appraisal framework for critiquing quantitative and qualitative papers.

The literature search results are attached as Appendix B, and the synopsis table of summarised articles as Appendix C.

2.2 The intensive care unit where dying and death occurs

The intensive care unit represents a place where critically ill patients are treated with life-sustaining therapies in an attempt to potentially reverse their illness. Despite these goals of intensive caring, the number of patients dying in intensive care units is significant, ranging from 1 in 5 to as high as 1 in 3 patient deaths (ICNARC, 2009; Wunsch, *et al.*, 2005).

When a patient no longer responds to maximum supportive treatment, the decision to withdraw treatment is made based on the ethical principle of futility as further treatment is deemed futile. In the United Kingdom the number of deaths related to withdrawal of active treatment in ICUs reflected a figure of 9.6% (Wunsch, *et al.*, 2005; Pattison, 2006). As a result of contemporary intensive care provision which affords life-sustaining treatments and advanced nursing care, there appears to be a dramatic increase in the occurrence of withdrawal of treatment within ICUs, as opposed to death despite full active medical management (Stroud, 2002; McGloin & McLeod, 2010).

Advances in critical care nursing expertise, advanced technology and treatment options have increased the number of patient admissions in ICUs who receive life-sustaining treatment despite having a poor prognosis and being in a futile situation (Stroud, 2002; British Medical Association [BMA], 1999). This, in turn, has increased the incidence of withdrawal of treatment in ICUs as opposed to death despite full active management (Stroud, 2002; BMA, 1999). A medical crisis soon develops when a patient becomes critically ill and presents with a haemodynamically labile clinical picture. In the UK this usually necessitates admission to an ICU for advanced medical, nursing and technological life-sustaining therapies. However, many patients deteriorate despite maximum therapies and fail to survive (Efsthathiou & Clifford, 2011). Besides overcoming the admission crisis to the ICU, critical care nurses need to manage withdrawing treatment and the negotiation of death which produces stressful and emotionally distressing experiences (Stayt, 2009). Mortality rates in adult intensive care units in the UK reflect an approximate figure of 17%, demonstrating a need for end-of-life care within the ICU (Pattison, 2004; ICNARC, 2010). An integration of critical care and palliative care therefore exists at a dying patient's end of life.

Patients with chronic illnesses experience numerous exacerbations, only to be rescued from the brink of death by sophisticated technological interventions in the ICU (Miller *et al.*, 2001). This unpredictable nature of chronic illness disguises the dying trajectory, creating what Callahan (1993) refers to as the vanishing line between life and death, where death is no longer experienced as a natural outcome, but rather as an inadequately treated disease, a failure of modern medicine. From my own previous experience within clinical practice, this viewpoint was often apparent among medical and nursing personnel when the decision to withdraw treatment was made.

2.2.1 Good end-of-life care

Auger (2007) and Seymour (2001) described an 'unnatural' death as one where the patient was attached to life-sustaining equipment in a hospital environment such as an ICU, being cared for by strangers. The patient in this unnatural dying situation is not autonomous or aware of their impending death, but is kept pain free and comfortable in an attempt to ensure a good death, which is embedded in the philosophy of palliative care. However, according to Halcomb *et al.* (2004) a good death, one that is pain free, should be perceived as a clinical success. Nurses continue to face the daily clinical and emotional challenges of redirecting their efforts from cure to dignified end-of-life care when death is inevitable. The findings from research conducted by Halcomb *et al.* (2004), Puntillo *et al.* (2001) and Kirchhoff *et al.* (2000) all concern a common theme regarding good end-of-life care which is to ensure a pain free, comfortable and dignified death for the dying patient in the ICU. However, technology may improve the trajectory of death when striving towards an 'ideal' death in the ICU. This can be achieved by not shortening or prolonging the dying process; ensuring technical death is aligned to bodily death by ensuring all

avenues of treatment have been exhausted before treatment is withdrawn; ensuring the family have accepted the patient's impending death; and staggering technological control in such a way as to facilitate a gradual, quiet and dignified dying trajectory (Seymour, 2001).

I believe good end-of-life care also includes informative explanation regarding the rationale behind this transition from curative to palliative care measures with the intention of creating an environment for a dignified dying trajectory for the patient whilst supporting a family. Previous clinical experience has taught me that families take comfort in this invasive technology because it is familiar to them. Sometimes, a family may request the removal of the invasive tubes and lines prior to withdrawal of treatment. In the event of such a request the family's wishes are respected.

Good end-of-life care also necessitates effective communication and establishing a close bond between the family and the nurses to assist the family to cope with the reality of the patient's poor prognosis and impending death. During times of crisis and stress, families may also seek meaning-making rituals that comfort them during this intense and traumatic situation (Chambers and Curtis, 2001). Rituals performed by critical care nurses control the clinical environment where nurses often find comfort in their familiarity with the advanced technology, and the use of this technology enhances the family's confidence that everything is being done for the patient (Chambers and Curtis, 2001). This technology provides nurses with a tool for seeking meaning out of critical illness and death: ritual serves as a social defence system protecting nurses against the anxiety that is caused by human suffering (Suominen *et al.*, 1997; Chambers & Curtis, 2001).

In some ICUs a yearly memorial service is conducted to remember the patients who had died in the ICU. This ritual places the patient's death, which is seen as a routine occurrence in the ICU, within a broader human context, thus helping the staff

to make meaning out of the extraordinary death of a human being which has taken place in the ordinariness of the daily activities of the ICU. Holland (1993) suggests ritual is used as a vehicle for social change and may be viewed as protection from anxiety, maintaining social order through reinforcing cultural and social structure, and understanding its survival through change.

The intensive care unit reflects a social life world comprising critically ill patients, advanced technology and expert clinical practitioners where ritual and evidence-based practice co-exist within clinical practice. Perhaps the most effective rituals arise from the depth of our human experience (Chambers and Curtis, 2001), and in the modern climate of advanced technological nursing, nurses often struggle to find ways to give form and meaning to dying and death within the intensive care milieu.

2.2.2 Temporality and spatiality

In a phenomenological study conducted by Vouzavali *et al.* (2011), the close connection between the critical care nurse and patient was mediated by the immediacy of the body and the gaze. Intensive care patients are unable to communicate and thus manifest themselves through their bodies, where the body is the only path of association and it is through the body that a relationship is formed between the nurse and patient (Vouzavali *et al.*, 2011). Symbolically, the body may be perceived as the place where the patient suffers, and the mouth constitutes the point where the inner and outer worlds converge and is a symbol of the human power to communicate (Cirlot, 1995). Nurses perceive the handling of the patient's body and fluids at a deep level, as an approach to a patient's soul, thus extending the connection beyond the body and encompassing psychological and spiritual dimensions (Vouzavali *et al.*, 2011).

The nurse within the ICU experiences a unique relationship with the patient, and the relationship is invested with meaning which elicits powerful feelings during the patient's subsequent intensive care journey (Vouzavali *et al.*, 2011). Critically ill patients are central to nurses' meaning-making process and role perception, and the use of the 'therapeutic self' is a mechanism whereby critical care nurses communicate with sedated ventilated patients (Scholes, 1996; Vouzavali *et al.*, 2011). Suffering and anxiety are everyday companions of nurses, and the process of empathising with patients during intense suffering often leaves hurtful imprints on the nurses (Vouzavali *et al.*, 2011). This is especially true regarding the concept of dying and death. Nurses need to face their own fears of death before they can support patients and families to deal with death. Critical care nurses are present at the patient's bedside 24 hours a day, caring for the patient, conducting intelligent observation, assessing, planning assessment, and planning and implementing the various treatment regimens. The nurse is also responsible for supporting the patient's family and keeping them informed of the patient's condition whilst conducting constant minute-by-minute holistic care. The critically ill patient 'becomes' the domain of the nurse, and defines the limits of a nurse's activity, emotions and lived world while in the ICU (Vouzavali *et al.*, 2011). This sense of closeness and ownership denotes both the nurse's focus of time and temporality, as well as the presence in a special 'space' or spatiality that is shared with the patient (Vouzavali *et al.*, 2011). The therapeutic self, temporality and spatiality are salient aspects within nurses' roles in the intensive care milieu.

Space is multidimensional according to Vouzavali *et al.* (2011), thus providing both housing and refuge; and in a symbolic sense, the patient becomes the 'place' where the critical care nurse may self-develop and grow. According to critical care nurses' perceptions, the patients' bodies and beds become a meeting ground, which

belong neither to the patient nor the nurse, but to their synergistic relationship (Vouzavali *et al.*, 2011). The shared time spent with a critically ill patient is awash with forceful experiences, implicit encounters and strong feelings impenetrable to others. These experiences of caring permeate nurses' self-perception, and personal and professional identity, and profoundly affect the way critical care nurses interpret their world (Vouzavali *et al.*, 2011). Symbolically, an intimate bond exists between the nurse and patient as a unity where the nurse and patient occupy the same space in time.

Zerubavel (1979) describes the hospital as a modern formal organisation with a highly complex social system which is characterised by an elaborate division of labour. Health and illness are symbolically located in the sacred domain of almost every culture, and the temporal order which exists in hospital life is oriented towards patient coverage (Zerubavel, 1979). Nurses are constantly at the patient's bed space on a 24 hour basis, seven days a week. During periods of tea/coffee and meal breaks, patient care is handed over to a 'covering' nurse who cares for the patient in the allocated nurse's absence. There is a marked difference in patient coverage between doctors and nurses. Doctors spend a minimal amount of time at the patient's bedside as compared to the nurses and spread their time among all the patients in the ICU, either conducting a procedure or reviewing the patient's ICU chart, whereas nurses are in constant attendance but occasionally leave the bed area to replace infusions, check blood gases or help another nurse with patient care. Time is a major parameter of social order with social life structured and regulated in accordance with it (Zerubavel, 1979). The function of the handover is to ensure the continuity of patient care by communicating pertinent information to the nurses on the oncoming shift. At the start of a shift, the charge nurse of the previous shift presents a 'global' handover of all the patients in the ICU. The charge nurse of the oncoming

shift then delegates a patient to each nurse on duty. The nurses proceed to their allocated patient's bed space and receive a comprehensive patient handover explicitly referring to the individual patient's needs and therapies.

The concept of temporality is a common feature of social organisations, with the rhythms of organisational life having particular moral and cognitive dimensions, beyond simple regulative functions (Zerubavel, 1979). Individuals customarily adapt to a variety of contexts for anchoring events in time, and this socio-temporal order is an inherent constituent of social life (Zerubavel, 1979), especially in the temporal patterning of nursing activities such as the administration of medication, handover, writing reports and on/off duty rotations.

2.3 The dying patient in the intensive care unit

The art of caring for a dying patient in the ICU, together with the ever changing patterns of dying, pose significant challenges in the delivery of modern healthcare because nurses experience a juxtaposition of curative and palliative care within current clinical practice. Nurses not only manage complex disease entities and emergency scenarios which arise in critically ill patients, but also manage the patient's dying and subsequent death during end-of-life when treatment is withdrawn. Critically ill patients deteriorate quickly and the transition from critical illness to futility, and the process of dying following the decision to withdraw treatment, may be rapid (Pattison, 2006).

Philpin (2007) conducted an ethnographic study which explored ambiguity in the intensive care nursing culture and her findings highlighted the coexistence of ritual and symbolism within the technical and research-based elements of nursing care. An uncertainty surrounds the boundary between life and death in the ICU, a situation which is further complicated by the fact that life, in this instance, necessitates life-

sustaining therapies using various types of invasive technology and monitoring (Philpin, 2007).

Philpin (2007) draws her analysis of ambiguous boundaries in the ICU on the anthropological concept of liminality (van Gennep, 2004) and briefly states that in van Gennep's (2004) theory of rites of passage, the liminal state ('ambivalence') refers to a stage between separation from normal life and preceding re-incorporation back into the community. The critically ill patient who is about to undergo withdrawal of treatment may be perceived to inhabit this liminal state, a 'betwixt and between' state, between life (albeit sustained by technology) and death (which ensues following the withdrawal of life-sustaining therapies). During the orchestration of withdrawing treatment, the dying patient, the nurse and family could be perceived to be in a state of liminality as described by van Gennep (1909), and on a shared liminal journey. The patient, nurse and family are therefore in a 'betwixt and between' state, between life and death. The nurse who institutes the withdrawal of treatment is aware of the patient's impending dying trajectory, whereas the patient is usually unaware of their own death due to the analgesic and sedative infusions administered and their haemodynamically labile status.

Van Gennep (1909) identified three rites of passage: the rites of separation, transition and incorporation. During withdrawal of treatment the rite of separation has occurred and the patient is in this transitional betwixt and between state, a state of 'social limbo' which Turner (1969) describes as neither in one state or another – a state between life sustained by technology and an impending death. The nurse's liminal state during the management of withdrawing treatment is also 'betwixt and between' life and death, as the nurse withdraws life-sustaining therapies in an attempt to 'mimic' the natural process of dying. Nurses are positioned on the threshold between life and death as they manipulate sedative and analgesic

infusions during this state of social limbo. Death is omnipresent; the time, however, is unknown. Holland (1993) highlights the importance of the liminal phase in Turner's (1969) analysis of ritual as a reinforcement of the social order and also as a source of social change in the death of the patient. The nurse accompanies the patient and supports the family during this dramaturgical dying trajectory from the onset of withdrawal of treatment until death. The patient's care is concluded after death by performing the post mortem care. This is the nurse's final contribution to the care of the patient.

Turner (1967) further developed van Gennep's concept of liminality, describing patients in this transitional state as 'liminal personae' (threshold people) who, by virtue of their ritually polluting condition (critical illness), are frequently removed to a different place (the ICU) from ordered society. In Philpin's (2007) qualitative study this concept of pollution was perceived as the critically ill patients lay motionless in the ICU attached to the technology which penetrated their bodies, exposing and opening up previously unseen areas to the medical gaze, thus rendering them vulnerable. Patients' bodily fluids from their penetrated bodies were also viewed as a pollutant substance (Philpin, 2007). However, the nurses in Philpin's (2007) study spoke to the sedated and unconscious patients as if they were awake and able to respond. Further findings from the study revealed that the critically ill patients resembled 'cyborgs', attached to invasive technology and monitoring devices which penetrated every orifice of their bodies. In an earlier study, Haraway (1991) described a cyborg as a hybrid between machine and organism, and this notion of a hybrid suggests a liminal state of neither one thing nor another, an ambiguity at the boundary between life and death. More recently Blows *et al.* (2012) conducted a narrative review of literature that drew on the concept of liminality as a framework for understanding the experience of cancer survivorship. Cancer patients undergo a

state of liminality or rite of passage during their treatment trajectory from their initial diagnosis, throughout their treatment regime and to long-term survivorship (Blows *et al.*, 2012).

2.4 Death in the intensive care unit

2.4.1 Social death

Hallam & Hockey (2001) explored the notion that death was a disturbance of the social order, a laceration of the social body, and a gap in social and family networks. Aries concludes by positing the image of medicalised death as the icon of the 'bad' death where the 'death of the patient in hospital, covered with tubes, is becoming a popular image of macabre rhetoric' (1976, p. 614). Whilst I agree with Aries that the patient in the ICU is engulfed by a vast array of technology and invasive tubes and devices, I would argue that nurses attempt to alleviate the anxiety experienced by the patient's family regarding this strange environment. Nurses explain and educate the patient's family regarding these multiple invasive technologies and therapies from the outset when the patient is admitted to the ICU. This is done in an attempt to keep the family informed of the day-to-day management of the patient and to socialise them into this strange and frightening environment. The longer the patient's stay in ICU, the more informative and familiar the environment becomes for the family. The patient is unaware of the surrounding environment due to their critical illness state which necessitates the administration of sedation and analgesic therapies. This induces a state of unconsciousness or social limbo where the patient is also rendered aphonic due to the insertion of an artificial airway.

The British sociologist Walter discusses three cultural responses to death which he defines as traditional, modern and neo-modern (Walter, 1994). These represent the three contexts of a trajectory of dying, which are the bodily, social and authority contexts (Walter, 1994; Auger, 2007). The dying trajectory following withdrawal of

treatment in the ICU may be perceived as modern, hidden and controlled. Aries (1976) suggests the emerging attitude towards death in the twentieth century was one of death denial or invisible death where most people die in hospitals rather than at home (Auger, 2007). The dying person is removed from the community, dying and death are hidden, and the care of the dead moves from the private realm of the home to the public domain of healthcare professionals and the hospital environment (Aries, 1976; Auger, 2007). This concept of hidden death is especially apt with regards to the dying patient undergoing withdrawal of treatment in the ICU.

Glaser and Strauss (1965, 1968) and Sudnow (1967) conducted studies that reflected the ways in which social death was accomplished in acute hospital settings. Sudnow's (1967) research concerned the social action of dying, and argued that dying places a frame of interpretation around people resulting in social death practices that serve to isolate them. Aries (1976) stated this was the general attitude of western societies towards death, which was characterised by fear and shame. The inherent complexities of the ICU create a problem for dying patients. However, from my clinical experience, maintaining privacy for the patient and family during the dying trajectory following withdrawal of treatment posed challenges for nurses due to the busyness of the ICU. Thus the closure of curtains around the patient's bed space served symbolically as a 'traffic light' system with regards to dignity and respect during the patient's dying. Organisational needs played a part in isolating the dying patient. There was an ever increasing demand for intensive care beds to treat critically ill patients from the ward areas. Occasionally, a dying intensive care patient following treatment withdrawal was transferred to a side room on a ward because the intensive care bed was required for another patient. Sudnow (1967) and Glaser and Strauss (1965) described how nurses and doctors practised avoidance of the dying situation through pretending to deliver information and attention to routine tasks.

From personal experience I believe that critical care nurses adopt an open awareness towards discussing and managing dying and death in the ICU. In my previous experience, families were kept informed of the patient's condition throughout the patient's intensive care journey and were included in all aspects of discussions relevant to the possibility of treatment being withdrawn. Sudnow (1967) explained the notion that the associated meanings pertinent to the dying process and death were actually the product of social interaction. Dying was socially defined by doctors and nurses in that the actual moment of biological death became temporally dissociated from the moment of social death, and as a result the patient was treated and perceived as if biological death had already occurred (Sudnow, 1967).

Auger (2007) stated biological death was determined to some extent by medical technology, whereas social death remained difficult to define because individuals were not always aware of its occurrence in their lives. Glaser and Strauss (1965) explored the question of whether people could die socially before they died biologically and what this meant for human relationships. In 1965, Glaser and Strauss published '*Awareness of Dying*', and uncovered a social process termed 'awareness contexts'. Critical to their theory was the recognition that dying was a social process that occurred over time. Critically ill sedated patients are usually unaware of their impending death which may be interpreted as 'closed' awareness, whereas the patient's family experience 'open' awareness towards the patient's dying trajectory through discussion and explanation with the intensive care personnel. Nurses maintain professional composure by managing their emotional involvement with the patient according to their expectations regarding the patient's death (Goopy, 2006). The intensity of intensive care work helps to take a nurse's mind off the patient's fate, thus reducing the nurse's conscious involvement and helping maintenance of composure during this fraught and fragile time of withdrawal of

treatment (Goopy, 2005). Additionally, nurses rely on each other for mutual support to maintain their composure and to be reassured that everything conceivable has been done for the patient.

2.4.2 Being in control

Once the decision has been made to withdraw treatment, it is documented on the patient's prescription chart which serves as a legal requirement. A specific trajectory follows the decision. The orchestration of withdrawing life-sustaining therapies then becomes a nurse-led practice. The patient's family is informed that a decision has been made relevant to the patient's further treatment options, and their presence is requested for a formal meeting where the decision will be discussed with them by the consultant anaesthetist and nurse caring for the patient. This meeting follows the format of breaking the news to the family. The family should have been made aware of the patient's progress and updated at regular intervals throughout the patient's intensive care journey. Families do not suddenly switch from hope, survival and cure to the acceptance of impending death. This occurs gradually over a varying period of time which may range from hours to weeks to months. Shorter and Stayt's (2009) phenomenological study suggests the format nurses follow in preparation for the ensuing withdrawal of treatment practice affords a means of feeling in control of a situation. Shorter and Stayt (2009) highlight that intensive care deaths were usually expected in the ICU as compared to a death on a general ward. In addition, nurses felt that being prepared for the patient's death made the experience less traumatic and more controlled (Shorter and Stayt, 2009). Being in control of the dying trajectory was also evident in an earlier study conducted by Costello (2006) who found expectedness and preparedness were perceived as elements of a good death by the nurses. I believe nurses do take control of the patient's dying trajectory through

preparing for the withdrawal process by removing unnecessary equipment from the patient's bed space, which in turn facilitates space for family vigilance; orchestrating the withdrawal of therapies; and nurturing the dying patient and family behind the protection of the closed curtains. Shorter and Stayt (2009) conclude that repeated exposure to death in the ICU may lead to emotional disengagement from caring for the dying patient, which may impact on the quality of care for the dying patient and their family. However, I believe critical care nurses are concerned with the salient issues of human dignity, open effective communication with the patient's family and the use of advanced assessment skills to deliver optimal, advanced technological treatment options, whilst remaining respectful of each patient's individual, holistic needs and bodily integrity. Seymour's (2001) findings confirmed that critical care nurses attempted to ensure dignified end-of-life care for dying patients when no further curative options were available.

2.4.3 Viewing death as a failure

Understanding the role of embodiment in social life requires recognition that our bodies give us both life and death, so that social and cultural life can be understood as a human construction in the face of death (Seale, 1998). Furthermore, the intensive care culture is primarily one of using advanced technology to save lives and increase the patient's chances of survival. For many nurses, discussions relevant to dying and death appear difficult in this technological, aggressive care setting where personnel may feel that a patient's death reflects poorly on their skills and represents a failure on their part to save the patient's life (Curtis and Patrick, 2001). Discomfort in discussing death appears to be universal and not a problem unique to intensive care nurses alone, as it is rooted in society's denial of dying and death (Curtis and Patrick, 2001). Conversations pertinent to dying and death are often viewed as

socially unacceptable in modern society, especially in an intensive care environment where death is treated as a disease or an enemy. Critical care nurses engage in a battle against death in order to rescue the patient back to life and feel a deep sense of disappointment or defeat when the patient dies (Vouzavali *et al.*, 2011). However, death appeared easier to accept when the patient had multiple risk factors and was unresponsive to maximum treatment therapies (Ranse *et al.*, 2011). Acknowledging defeat is often difficult within the embedded rescue culture of intensive care clinical practice. Experience and wisdom, combined with open pragmatic discussions pertinent to ethical and moral considerations of futility, make the decision to withdraw treatment somehow easier. Patients with chronic illnesses experience numerous exacerbations, only to be rescued from the brink of death by sophisticated technological interventions in the ICU (Miller *et al.*, 2001). As previously stated, the unpredictable nature of chronic illness disguises the dying trajectory, creating what Callahan (1993) suggests is the vanishing line between life and death, where death is no longer experienced as a natural outcome, but rather as an inadequately treated disease, a failure of modern medicine. This viewpoint is often apparent among medical and nursing staff when the decision to withdraw treatment is taken.

Halcomb *et al.*'s (2004) Australian study involved the lived experiences of ten intensive care nurses, and found that nurses did not perceive death from withdrawal of treatment as normal in the ICU as they were left to support the family psychologically whilst simultaneously dealing with the technical aspects of withdrawing treatment from the patient. A significant limitation of this study was the over-representation in the sample of nurses who had positive experiences with end-of-life and were more likely for this reason to participate in the study. However, the strength of this study lies in the findings which suggest withdrawing treatment represents a personal and professional struggle for nurses, and that debriefing and

education about withdrawing treatment would be beneficial to both staff and families and thus potentially improve patient care and reduce the burden on nurses.

Critically ill, sedated patients who undergo mechanical ventilation with an artificial airway in situ are usually unable to communicate verbally due to their unconscious and aphonic state. There is a close connection between the nurse and a patient through the immediacy of the body and the gaze (Vouzavali *et al.*, 2011). Although sedated and ventilated, these patients are able to be aroused from their sedated state by manipulating the dosage of the sedative infusion. However, in some patients who are in a haemodynamically labile state this may not be possible. Cirlot (1995) affirms that 'watching' is symbolic of understanding, while 'gaze' symbolises the development of empathy. The nurse and patient reveal themselves through their eye contact, a mutual gaze that encompasses each other's world, care and intimacy with the eyes symbolising the path to the body and the soul (Feuillet, 2007).

I recall from previous clinical experience that many patients would follow me around with their eyes whilst I was caring for them. It would appear that through the body a relationship develops between a patient and a nurse (Vouzavali *et al.*, 2011). Additionally, the continuity of care and a nurse/patient ratio of 1:1 provide an ideal opportunity for the development of an intimate relationship between the nurse and a patient. Through this mutual gaze a deeper communication and understanding are achieved, a bond develops when oral communication is not possible, and empathy is mediated by the mere sight of and contact with a patient's body and often their gaze (Vouzavali *et al.*, 2011). The intensive care nurse develops a close relationship with the critically ill sedated patient by collating information pertinent to the patient's disease entities, individual assessment of holistic needs, treatment profile, case notes and explanations from the family. Family members share the patient's life story

with the nurse, and this offers an increased understanding of the patient as an individual and symbolically clothes the critically ill patient's personality.

The use of technological life support creates an interlude during which people strive to harmonise their understandings, expectations and plans for the patient (Cook, 2001). Family members often need time to overcome denial that the patient is dying and disbelief that treatment options no longer exist, or to restore healthy family dynamics. Early on during the patient's ICU journey, technological support is collectively viewed by the patient's family as saving life and 'doing everything', rather than as specific technological tools with specific therapeutic uses, thus representing a global approach to achieving the goals of care (Pattison, 2011). During the withdrawal process, the use of this technology could be viewed by the family as 'stopping everything', which may appear upsetting and undignified, as the goal of technology thus appears to shift from saving life to inducing pain or prolonging death (Cook, 2001).

2.4.4 Time to death

Unnecessary suffering and ineffective communication at end-of-life in the ICU is thought to be due to the difficulty of identifying the perfect time to implement the shift from a cure focus to comfort-oriented care (Efsthathiou and Clifford, 2011). Providing end-of-life care following cessation of treatment is further complicated because of the short duration of the patient's dying phase. The risk of a sudden imminent death does not allow for preparation for death as it places enormous demands and challenges on the nurses, who are expected to deliver high quality palliative care for the dying patient and bereaved family in a very short time (Neuberger, 2003; Morgan, 2008).

In 2005, Wunsch *et al.* conducted a quantitative cohort study in 127 adult general intensive care units in England, Wales and Northern Ireland with a sample of 118,199

patient admissions to ICUs. The decision to withdraw treatment was made for 9.9% of the patient sample and 30.8% of patients died following the decision to withdraw treatment (Wunsch *et al.*, 2005). The study indicated withdrawal of treatment was widespread in ICUs in the UK, and the median time to death following withdrawal of treatment was 2.4 hours with 8% of patients surviving for longer than 24 hours (Wunsch *et al.*, 2005). The authors recommended guidelines for withdrawing treatment which would facilitate uniform decision making. Some ICUs in the UK do adhere to specific guidelines; as expected, these serve as a guide only. Winter & Cohen (1999) suggested the timing of withdrawal, the treatments withdrawn and the manner of withdrawal may vary from country to country, and also between ICUs in the same country and in the same hospital. Reasons for this variation arise from differences in the law surrounding end-of-life decisions, and the organisational and cultural norms that exist within the different ICUs (Seymour, 2001). Patients who survive longer than expected following withdrawal of treatment are often transferred out of the ICU to a ward with more privacy, but the family should be prepared for the move as this situation presents several dilemmas for families and the intensive care team. Prolonged survival often causes those involved in caring for the patient to question their decision to withdraw life-sustaining treatments (Rubenfeld and Crawford, 2001).

Critical care nurses experienced in caring for dying patients in the ICU are often highly skilled in undertaking withdrawal of treatment and palliative management (Pattison, 2011). Less experienced nurses within the intensive care team require mentoring from the more experienced nurses and peer support to enable them to undertake the challenges of providing care to a dying patient in a confident and competent manner. In an earlier comparative ethnography of intensive care and obstetric settings in the UK, Harvey (1997) describes how intensive care nurses

engage in a strategic practice of withdrawing life-sustaining support slowly in order to mimic the decline of 'natural' death and in accordance with culturally prescriptive norms about the proper course of 'natural' dying.

Pattison (2011) argues that critical care nurses can be expert in end-of-life care and should be leading this care by having a mastery of the necessary clinical knowledge and understanding of the ethics, so that they can advocate for patients and families in what can often be difficult death and dying scenarios. Latour *et al.* (2009) conducted an attitudinal survey on the involvement of European intensive care nurses in end-of-life decisions and the extent to which their nursing practice was based on shared beliefs, experiences and attitudes. A total of 419 questionnaires were distributed to delegates at an international critical care nursing conference, yielding a response rate of 39.1%. The majority of respondents were involved in the decision-making process (73.4%) and this involvement positively influenced their job satisfaction (Latour *et al.*, 2009). Of the population sample, 78.6% disagreed that dying patients should be transferred out of the intensive care unit merely to use the bed for another critically ill patient (Latour *et al.*, 2009). In reality, due to organisational needs, the bed is often needed for another critically ill patient; this then necessitates transferring the dying patient out of the ICU to a ward area. Generally the nurses' views and experiences of end-of-life care were similar, with the exception of the provision of nutrition and use of sedation (Latour *et al.*, 2009). This issue of nutrition and sedation differed between countries, and Latour *et al.* (2009) suggest it is relevant to how autonomous the nurses were in their practice. According to the participants' responses, British critical care nurses appeared more autonomous in their clinical practice as compared to their European counterparts (Latour *et al.*, 2009). The authors recommended further research in order to have a deeper

understanding of the cultural differences and the impact on end-of-life decisions, nursing care and best practice (Latour *et al.*, 2009).

Langley *et al.* (2013) conducted a more recent replication of Latour *et al.*'s (2009) study in South Africa which investigated critical care nurses' views on end-of-life decision-making and practices. The results indicated that 86% of the nurses felt that the family should be involved in the decision-making process and 76% of nurses were directly involved in the end-of-life care of dying patients. Miller, Forbes and Boyle (2001) suggest improving end-of-life care requires cultural changes, and that critical care nurses need an understanding of these complex cultural issues to bring about this change in their ICUs and also in their individual practice (Miller, Forbes and Boyle, 2001). Vouzavali *et al.* (2011) elicit the possibility that patients' death appears to drive critical care nurses to experience both their personal and professional life in a more authentic way.

2.4 Summary

Although an intensive care milieu represents a place where critically ill patients are treated with life-sustaining therapies in an attempt to potentially reverse their illness, when a patient no longer responds to maximum life-sustaining treatment, then the issue of withdrawing treatment arises. Death is viewed as a disturbance of the social order, a laceration of the social body, and a gap in social and family networks.

Nurses face clinical and emotional challenges when redefining their efforts from cure to dignified end-of-life care when death is inevitable. The critically ill patient and nurse share a space in a specific time frame from the beginning of the patient's intensive care journey until death. The therapeutic self, temporality and spatiality are salient aspects within nurses' roles in the intensive care milieu.

Throughout the patient's treatment withdrawal and dying trajectory, the patient, nurse and family may be perceived to be in a state of liminality, in a state 'betwixt and between' life and death.

Nurses strive to ensure a good death following treatment withdrawal in an appropriate environment for dignified dying to occur. Nurses perceive that being in control of the patient's dying trajectory, being prepared and knowing what to expect are elements of a good death.

Chapter 3 is a continuation of the literature review.

Chapter 3: Decision making and withdrawal of treatment

3.1 Introduction

Chapter 3 continues the discussion relevant to the following themes from the literature review: decision making about the withdrawal of treatment; the nurses' role in decision making and withdrawing treatment; and, finally, withdrawal of treatment and the family. The research question, aim and objectives for this study are also included in this chapter.

3.2 Withdrawal of treatment decision making

The literature suggested that futility occurred in healthcare when therapies appeared ineffective and served no further purpose (Coombs *et al.*, 2010). In the United States early attempts to determine futility were based on the use of specific clinical criteria, for example the Simplified Acute Physiology Score [SAPS] and Acute Physiology and Chronic Health Evaluation [APACHE] (Burns & Truog, 2007). This was then followed by a focus on procedural and ethics committee approaches to determine futility of treatment in critically ill patients (Coombs *et al.*, 2010). In the UK, the APACHE scoring risk assessment was in use. Whilst the American perspective on futility was well documented, there was less clarity on specific frameworks for critically ill patients in the UK, despite similar rates of treatment withdrawal due to medical futility (Coombs *et al.*, 2010). Accepting the futility of continued treatment for critically ill patients may have induced a sense of failure in nurses, especially when patients had deteriorated to the point of dying, and their critical illness had not been resolved or reversed. Pattison (2011) explicated this issue by saying that this often permeated feelings of guilt, frustration and anxiety about the decision making process. The futility issue arises in the ICU when medical and nursing personnel are at different points of awareness regarding a patient's unresponsiveness to maximum therapies

(Coombs *et al.*, 2010). This ultimately necessitates a discussion regarding end-of-life care and the need for deciding the way forward in the best interests of the patient (Coombs *et al.*, 2010). Nurses were integral in redefining care from a curative perspective to a palliative focus in a response to meet the needs of a dying patient following withdrawal of treatment. In the UK, the patient's family was an integral part of the decision making process as their view on treatment withdrawal was sought and their opinion respected (Coombs *et al.*, 2010). This helped the intensive care team to understand the silent patient as an individual in the ICU bed, and to better understand what the patient's wishes were prior to their intensive care admission (Coombs *et al.*, 2010).

In 1999, the British Medical Association published advice and guidelines pertinent to withdrawal of treatment and the decision making process in ICUs; these considered the needs of medical and nursing personnel and the patient's family (Seymour, 2001). Against the backdrop of culturally and morally prescriptive ideas about 'natural' death, the role of technology in this event and the part played by different individuals, extensive concerns had been expressed by clinicians regarding the legal and ethical implications of withdrawing life-sustaining treatment (Timmermans, 1998; Seymour, 2001).

Furthermore, guidelines for withdrawing treatment in the UK were clearly set out in a document compiled by the Intensive Care Society (2009). These guidelines broadly suggested medical treatment should be founded on compassion and in the best interests of the patient, with effective communication, collaboration and agreement between multi-disciplinary colleagues, patients and families (ICS, 2009). However, they served as guidelines only. The decision to withdraw life-sustaining treatment involved many factors, and should usually be taken after consultation with members of the critical care nursing and medical teams where a consensus should

be reached by the entire team involved in the management of the patient's care. Prior to commencing withdrawal of treatment, the significance of the patient's poor prognostic factors must be explained and discussed with the family, allowing them time to come to terms with their impending loss. The family should be informed of the rationale which led to the decision and be in agreement with the decision. The final decision and responsibility remains vested in the consultant in charge of the ICU at the time, and the current law within the UK allows a competent and experienced physician to make this decision to withdraw treatment (ICS, 2009). The patient's diagnosis was the responsibility of the doctor; however, the responsibility of managing the withdrawal of treatment resided with the nurse at the bedside (Coombs et al., 2010). It was imperative that the views of the patient (if known) and the family were considered during the decision making process in order to avoid conflict at this sensitive and emotive time. With the exception of Scotland, in the UK there presently exists no established role for surrogate decision-makers, although it is acknowledged that their input might be helpful in making decisions for patients who are not competent. In England and Wales, no adult can consent on behalf of another adult, whereas in Scotland a law was instituted in April 2001 allowing patient surrogacy (ICS, 2009). However, Lasting Power of Attorney (LPA) is applicable in the UK, as it allows an individual to appoint someone to make decisions on their behalf. It is normally executed when a person is non competent and unable to make their own decisions. The health and welfare LPA concerns the individual's medical care and refusing life-sustaining treatments.

Life-sustaining treatment was only withdrawn on clinical grounds when the treatment no longer benefited the patient or the expected benefits were outweighed by the burdens of treatment (ICS, 2009). Intensive Care Society (2009) guidelines further recommended that each decision to withdraw treatment from a critically ill

patient should be made upon its own merits, and not made on the basis of either cost or medical convenience. In the event of a patient who was not competent to express their wishes, the family was usually consulted in an attempt to discover them. On admission to the ICU, a comprehensive and succinct management plan was compiled for each patient's individual needs with set parameters for the administration of various therapies. This plan was reviewed and updated at least once a day. Ethically, no moral difference exists between withholding and withdrawing treatment, though many doctors feel more comfortable regarding withholding as compared to withdrawing treatment; this is because when the outcome is uncertain, it is worth considering a trial of intensive care treatment on the understanding that it will be withdrawn if ineffective (ICS, 2009).

Intensive care clinicians and nurses utilised pathophysiological parameters, patient response to treatment, deductive reasoning and sound ethical principles when considering the possibility of withdrawing treatment in critically ill patients (Cook, 2001). Withdrawal of treatment was therefore not a decisive event, rather an unfolding process whereby nurses managed the best death possible for critically ill patients under difficult circumstances (Pattison, 2011). The goal was concerned with the aesthetic, ethical and social experiences of those involved in the patient's care. It could be argued that this may be an unachievable outcome for all patients given the nature of each patient's risk factors, original diagnosis and prognosis. However, once the decision had been made to withdraw treatment, further decision making was handed over to the nurses to implement this transition from cure to comfort care. Withdrawing treatment may be managed to occur quickly or slowly, changing the tempo of the dying process and the pace at which life supportive therapies are withdrawn (Rubenfeld and Crawford, 2001). The sequential order of withdrawals may be dominated by concerns such as the potential suffering experienced by the patient,

vicarious suffering experienced by others, and the speed of the consequent death (Cook, 2001).

During the withdrawal of treatment, patient management continued in a compassionate and caring manner with sedative and analgesic therapies maintained for comfort and pain relief, but not at dosages that may intentionally hasten death. Treatments aimed at primarily maintaining organ function which may prolong death were withdrawn, for instance, cardiovascular therapies, renal filtration support, terminal respiratory weaning or terminal respiratory extubation. As interventions to improve end-of-life care and decision making develop, it is important to understand how they may interact within the intensive care culture, formal and informal rules, the meaning and uses of technology, roles and relationships amongst critical care personnel, and rituals such as intensive care rounds (Baggs *et al.*, 2007). The British Medical Association's (1999) guidelines on withdrawing treatment stressed the need for a consensus in decision making and highlighted the importance of good communication, both in the decision making process and the actual withdrawal of treatment (McLeod, 2014). The findings from Vincent *et al.* (2004) supported this stance that in the UK, end-of-life decisions were made by the multi-disciplinary ICU team where nurses played a valuable role in the decision making process (Puntillo & McAdam, 2006).

3.3 Nurses' roles in decision making and withdrawing treatment

Decision making remains one of the salient issues before end-of-life care is considered. Treatment withdrawal should where possible have incorporated a plan for end-of-life care, as most patients died two to four hours after treatment was withdrawn (Wunsch *et al.*, 2005). This narrowed the window for nurse involvement in shaping the dying trajectory for critically ill patients who had reached the point of

futility or treatment that no longer conferred any benefit (Pattison, 2011). Prior to treatment withdrawal, all distractions were eliminated or minimised so that the family were able to devote time and space to the dying patient. Families were offered explanations as to what could possibly be expected and anticipated during the patient's dying trajectory. In a qualitative study conducted by Coombs *et al.* (2010), the findings revealed that within the UK, patients' families were an integral part of the end-of-life decision making process, and their views and acceptance of the withdrawal decision were taken into account. In clinical practice, the decision making process was sometimes staggered and delayed to accommodate the family's request for another 24 hours of intensive care therapy before a reassessment was performed and the decision was confirmed. In my study the issue of delaying the withdrawal of treatment will be explored through the medium of a vignette.

In clinical practice, once the decision to withdraw treatment is confirmed, the nurse then arranges a family meeting where the consultant informs the family of the decision to withdraw treatment, and further explanations relevant to the patient's dying trajectory are usually left to the nurse to answer. Previous studies in ICU suggest nurses often felt alienated from the actual decision making process, possibly due to a power differential between the nursing and medical professions (Robichaux and Clark, 2006; Bach *et al.*, 2009; Latour *et al.*, 2009; Piers *et al.*, 2010) and were less satisfied with end-of-life care than doctors (Festic *et al.*, 2011). However, Latour *et al.*'s (2009) survey study did reveal that critical care nurses in the UK were more autonomous in the decision making process and withdrawing treatment than their European counterparts. Benbenishty *et al.*'s (2005) quantitative study investigated physicians' perceptions of the role of European critical care nurses in end-of-life decision making. A significant difference was found between the regions in Europe, with physicians in northern regions reporting more nurse involvement (Benbenishty *et*

al., 2005). The findings revealed nurses were seen to be part of the decision making process, but their participation varied in different countries, which concurs with Latour *et al.*'s (2009) study.

In an attempt to accomplish a good death, Truog *et al.* (2008) and Pattison (2011) recommended that critical care nurses should participate in the decision making process, which necessitated meaningful, proactive involvement in the planning and implementation of end-of-life care. This nursing involvement is especially apt in clinical practice whereby experienced nurses often take the lead to initiate the decision making process, and are instrumental in initiating the discussion pertinent to futility of further treatment. In Bucknall's (2000) observational study of 18 nurses in both urban and rural critical care settings in Australia, the findings suggested nurses' years of experience in ICU and seniority influenced their input to the decision making process. Certainly in current clinical practice, advanced critical care nursing expertise appears to be valued by most medical personnel, especially with the inclusion of the critical care consultant nurse role and the nurses who have many years of intensive care experience.

On a daily basis, critical care nurses dealt with ethical dilemmas, especially relevant to withdrawal of treatment practice. Patient autonomy was not always possible, as these critically ill patients were sedated and mechanically ventilated and were rendered unable to exercise their rights. However, their rights were respected exclusively through input from the family. There exists a clearly defined interface between the legal and ethical aspects of care interwoven in the professional code of nursing ethics as stipulated by the Nursing and Midwifery Council's [NMC] Code of Conduct (2008). These rules guide nurses' conduct or action in types of situation and circumstance, set prescriptive standards of how things ought to be and ought not to be, and apply to everyone within the nursing discipline. Law and ethics serve as

agents for social control using rules, principles and standards to prescribe behaviour and determine what kind of actions are prohibited, permitted or required (Hendrick, 2000). Nurses' abide by the code stipulated by their governing professional body and the laws of the country in which they live by their accountability and responsibility. The code of professional conduct envisages a portrait of a practitioner who has the capacity to challenge, the honesty to ask why, the empathy to care, the skill to perform competently and the determination not to be put down (Poncet *et al.*, 2007). Perhaps one reason why critical care nurses were hesitant to engage in decision making was due to it being an incredibly stressful event which could increase the nurses' risk of burnout (Poncet *et al.*, 2007). Furthermore, Stayt (2009) explained the notion of the emotional costs of labour: the social exchange and human interactions involved in family care during end-of-life induced stress in the nurses. Critical care nurses were at greater risk of suffering post-traumatic stress syndrome, possibly due to the combination of one-to-one ratio nursing; an advanced technological and high-pressured milieu; and the repeated exposure to stressful events (Mealer *et al.*, 2007; Pattison, 2011). A trusting and respectful relationship usually developed between the patient, nurse and family during the patient's critical illness journey in the ICU. Nurses ultimately balanced the needs of the dying patient following withdrawal of treatment against the needs of the family as they managed the patient's dying trajectory until death.

The Liverpool Care Pathway-Intensive Care Unit [LCP-ICU] (2007) was previously used as a prompt for critical care nurses in assessing and controlling symptoms during the dying trajectory, but it did not suggest how to undertake withdrawal of treatment, which varied considerably between (and within) ICUs and teams in the UK (Ellershaw, 2007; Pattison, 2011). The aim of the LCP-ICU was to improve care of the dying patient in the last hours/days of life by providing clear goals in the

management of physical, psycho-social and spiritual symptoms. Following the independent review of the Liverpool Care Pathway in July 2013, the Leadership Alliance for the Care of Dying People was set up in the UK to explore alternative end-of-life trajectories. Emphasis on end-of-life care always focused on the palliative focus of care pathway because the LCP-ICU pathway served as a mere guide.

Critically ill patients are usually unable to think and participate in decisions relevant to life and death due to their induced unconscious, sedated and mechanically ventilated state. As a result, much of the discussion about what was happening to the patient, and decisions about treatment or the withdrawal of this treatment, took place between the patient's family and the critical care physicians and nurses (Efsthathiou & Clifford, 2011). Under UK law, the ultimate authority over the non-competent adult rested with the treating physician rather than the next-of-kin, critical care nurses or the courts (Bell, 2007). However, critical care nurses were well placed to guide physicians in the decision-making process as they spend more direct time with the patient and family (Lautrette *et al.*, 2006). It was imperative that these nurses promoted a patient and family-orientated decision making approach where possible. This approach was viewed as a comprehensive ideal for end-of-life care within the ICU setting (Truog *et al.*, 2008).

Halcomb *et al.* (2004) explored the lived experiences of intensive care nurses as they withdrew treatment from critically ill patients in an ICU. The nurses did not view the patients' deaths as normal as they were left to support the family psychologically and simultaneously deal with the technical aspects of withdrawing treatment in the patient. A significant limitation of this study was the over representation in the sample of nurses who had positive experiences with end-of-life and were more likely for this reason to participate in the study. However the findings from the study suggested that some nurses experienced personal and professional struggles during withdrawal

of treatment. The findings of the study also uncovered a need for debriefing and education about the process of withdrawing treatment and reducing the burden on nurses. My study will explore nurses' experiences of withdrawing treatment from critically ill patients with a cultural perspective on a British ICU. This exploration will include how nurses redefine care and respond to the needs of a dying patient whilst supporting the family following the decision to withdraw treatment.

Technological life support creates an interlude during which people strive to harmonise their understandings, expectations, and plans for the patient (Cook, 2001). Family members often need time to overcome denial that the patient is dying, disbelief that treatment options no longer exist, or the restoration of healthy family dynamics. Early on, during the patient's ICU journey, technological support is collectively viewed by the patient's family as saving life and 'doing everything', rather than as specific technological tools with specific therapeutic uses, thus representing a global approach to achieving the goals of care (Pattison, 2011). During the withdrawal process, the use of this technology is viewed by the family as 'stopping everything', which may appear upsetting and undignified, as the goal of technology thus appears to shift from saving life to inducing pain or prolonging death (Cook, 2001).

Winter & Cohen (1999) suggested the timing of withdrawal, the treatments withdrawn and the manner of withdrawal varied from country to country and also between intensive care units in the same country and even in the same hospital. Reasons for this variation arose from differences in the law surrounding end-of-life decisions, and the organisational and cultural norms that existed within the different ICU's (Seymour, 2001). Intensive care teams had no control over the time to death as a result of treatment withdrawal because very little was known about the temporal features of dying and death (Rubenfeld & Crawford, 2001). Patients who survived

longer than expected following withdrawal of treatment could be transferred out of the ICU to a ward especially if the bed was needed for another critically ill patient from the ward areas. However, this necessitated explaining the patient's transfer to the ward personnel and to the family which often presented several dilemmas for families and also the intensive care team. In addition, Rubenfeld & Crawford (2001) stated that prolonged survival often caused those involved in caring for the patient to question their decision to withdraw life-sustaining treatments.

Pattison (2011) noted that experienced nurses who care for dying patients in the ICU were often highly skilled in undertaking withdrawal of treatment and palliative care management. Junior nurses within the intensive care team require in-house training to ensure they master these skills, which are achieved through mentorship, debriefing and peer support, to enable them to undertake the challenges of providing care to the dying patient in a confident and competent manner. In an earlier ethnographic study in an ICU in the United Kingdom, Harvey (1997) described how intensive care nurses engaged in a strategic practice of withdrawing life-sustaining therapies slowly in order to mimic the decline of 'natural' death and in accordance with culturally prescriptive norms about the proper course of 'natural' dying. The Intensive Care Society (2009) compiled guidelines for the withdrawal of treatment from intensive care patients in the UK. These guidelines are updated at regular intervals for clinical practice. Embedded within the decision making process is the interactional balance between disparate tensions and constraints of two divergent dying trajectories; technical and bodily dying, where the two must be aligned for death to occur at the right time (Seymour, 2001). Technical dying is based on the patient's blood results, haemodynamic monitoring evidence and other investigative evidence relevant to the patient. The patient's clinical signs and symptoms reflect bodily dying which is evidenced by recognition of the senses and informed by clinical

experience (Seymour, 2001). In the event of treatment withdrawal, technical dying usually occurs before bodily dying so that withdrawal of treatment is not seen to have any link to death (Seymour, 2001).

Nurses align 'body work' with 'emotional work' to reproduce the individuality of their unconscious dying patients during withdrawal of treatment, and in spite of the technological intensive care milieu, the dying trajectory can often be invested with an atmosphere of familial intimacy and meaning (Seymour, 2001). Emotional labour is a term used to account for the way nurses manage emotions so that they do not disrupt the normal work routine. Although emotional labour acts to regulate emotional expression, it also enables the emotional expression that is needed for good nursing (Seymour, 2001). Critical care nurses use emotional labour in the intensive care environment as a means for overcoming the dehumanising effects of dying in this biotechnological milieu (Simpson, 1997; Seymour, 2001). Through the development of a trusting relationship which develops between a patient, nurse and the family, nurses bridge the gap between the patient and their family during withdrawal of treatment and help the family to reconnect with the dying patient.

Accompanying the patient and family during the dying trajectory until death following withdrawal of treatment may be a deeply rewarding experience, especially when all attempts to ensure a comfortable, pain free and dignified death have been achieved (Henderson, 1966). During the patient's dying trajectory, nurses try to establish an ambience of intimacy and familial warmth between the patient and family. In addition, it is important to ensure that the ICU fosters a nurturing climate to support the emotional experiences of all personnel involved in withdrawal of treatment.

3.4 Withdrawal of treatment and the family

Suffering a critical illness in an intensive care unit is more than just a physical experience for the patient, their family and the nurse caring for the patient. In essence, a unique relationship usually develops during the patient's illness and embodies human, social and spiritual dimensions of holistic care. Following treatment withdrawal families of dying patients experience emotional distress and anxiety, a tendency towards denial of death and difficulties in understanding medical information (Rocker *et al.*, 2010). Effective communication and open, honest discussion assist the family to understand the rationale behind the decision making process and accept the futility of further treatment.

Lautrette *et al.*'s (2007) research draws attention to the importance of informative end-of-life meetings with the patient's family in order to discuss the decision to withdraw treatment from the patient. Lautrette *et al.*'s (2007) study involved family members of 126 patients dying in 22 ICUs in France. Subjects were randomly assigned to the intervention format of a customary end-of-life meeting and a brochure on bereavement to see whether it could lessen the effects of bereavement. The researchers also used a proactive communication strategy that included taking the time to listen to the family's questions and concerns (Lautrette *et al.*, 2007). This quantitative study suggested that by adopting this communication and listening strategy, the burden of bereavement may have been minimised (Lautrette *et al.*, 2007).

The issue of talking less and listening more during the meetings to break the news to the family were also highlighted in Seymour's (2001) seminal work. Seymour's (2001) study proposed that clinicians and nurses should ideally provide timely clinical prognostic information in order to support the patient and their family regarding withdrawing treatment in the ICU. This transition from individual responsibility to patient-focused consensus often permitted the family to understand,

perhaps reluctantly and with great sadness, that intensive caring sometimes involved letting go of life-sustaining interventions. During withdrawal of treatment, nurses also faced a dichotomy situation where they intellectually rationalised the decision to forgo treatment from critically ill patients as a palliative measure to prevent further burden from unwarranted treatment. However the issue of saving a patient from probable death proved to be difficult for intensive care staff to relinquish a controlled situation as this often induced a sense of failure in the nurses and doctors alike.

Kristjanson *et al.* (2001) conducted a study which examined factors that constituted a good or bad death, and found that the concept of trust accentuated the need for good and effective communication with the family. The patient's family were seen as an extension of the patient by the nurses. The close bond which often developed between a nurse caring for the patient and the patient's family assists the family to look back at this fragile time in a more positive manner (Ramsey, 2003). Good end-of-life may be viewed as an art and Levy (2001) suggested it is difficult to define, but you recognise it when you see it. Levy (2001) further emphasised that dying and death within the intensive care milieu raised the same anxiety and discomfort for critical care medical and nursing staff as for patients and families, yet the staff are not strangers to the process of dying and death. I believe that good end-of-life care is possible when nurses become involved in the decision making process. Hov *et al.* (2006) explored nursing intensive care patients on the edge of life and concur that few studies relevant to nurses' experiences of caring for dying patients in intensive care units have been undertaken. Moreover, very few studies focused specifically on critical care nurses' experiences of managing the withdrawal process and the patient's dying journey. Ranse, Yates and Coyer (2011) explored Australian nurses' beliefs and practices during end-of-life care in the ICU. Their findings suggested that the care of patients and their families during end-of-life was at the

core of the nurses' work, and that nurses played a pivotal role in supporting patients and their families in experiencing meaningful end-of-life care. The British study by Coombs, Addington-Hall and Long-Sutehall (2011) was conducted in two ICUs in England. Intensive care doctors and nurses were interviewed in this study which differed from the Australian study. The findings from the study revealed that patients who died in intensive care appeared to follow a three-stage dying trajectory. This involved the stages from admission with hope of recovery; transition from intervention to end-of-life care; and a controlled death (Coombs *et al.*, 2011). The authors suggested the focus of care should be on the transition from curative intervention to end-of-life care, rather than end-of-life itself, and that timely decision making was imperative within this clinical setting. This transition from cure to comfort care charted the dying trajectory as treatment was withdrawn. This transition from curative to end-of-life care following the decision to withdraw treatment will be explored in my study.

In Beckstrand's *et al.* (2006) study conducted in the United States, the participants were physicians, families and nurses. The findings suggested that there was a strong focus on comfort, acceptance of death and death with dignity during withdrawal of treatment (Beckstrand *et al.*, 2006). In a Canadian study of critical care nurses conducted by Lackie (2003), the author found that open and honest communication between physicians and with patients' families was an important element in ensuring a good death. The concept of a peaceful or good death in Thailand was perceived by nurses as raising awareness of dying; creating a caring environment in which to allow patients to die without aggressive treatment; and promoting end-of-life care aligned with patients' beliefs (Waraporn, 2009).

To provide a dignified death, it is reasonable to assume that dying patients in the ICU would want good symptom control and dignity and to be surrounded by their loved ones. From previous clinical experience, I would argue that caring for the dying

patient goes hand in hand with caring for the patient's family. As the various therapies are withdrawn during the dying trajectory, the nurse caring for the patient redirects this care to the family. The family require clear, timely and consistent information with regards to treatment withdrawal and the patient's impending dying trajectory and ultimate death. Additionally, they also need to be convinced that the dying patient is pain free and comfortable, and that the patient's wishes have been respected in order to find meaning in the death of a loved one (Rocker *et al.*, 2010). Spiritual support prior to the process of withdrawing treatment is afforded to patients and their families.

McMillen (2007) believes experienced critical care nurses have extensive experience in dealing with withdrawal of treatment and their viewpoints are usually respected by intensive care consultants. McMillen's (2007) study focused on nurses' contribution to end-of-life decision making and care in the UK. The findings revealed that nurses should be supported in their role and responsibilities to continue to provide care during withdrawal of treatment (McMillen, 2007). Patients and families feel comforted and nurtured by intensive care nurses who experience ease with the dying trajectory, who do not shrink back from honest, direct expression of grief, loss and uncertainty, and who present themselves in steadiness in the face of the patient and the family's fear and anxiety about dying and death (Levy, 2001).

Withdrawal of treatment decision making is documented on the patient's prescription chart which serves as a legal requirement. A specific trajectory follows the decision to withdraw treatment. The orchestration of withdrawing life-sustaining therapies then becomes a nurse-led practice. The nurse caring for the particular patient contacts the family and requests their presence at a meeting with the consultant anaesthetist where the decision to withdraw treatment is discussed. This meeting follows the format of breaking the news to the family. The family should have

been fully aware and informed of the patient's progress and updated at regular intervals throughout the patient's intensive care journey. Families do not suddenly switch from hope, survival and cure to the acceptance of impending death. This occurs gradually over a varying period of time which may range from hours to weeks to months. The format nurses follow in preparation for the ensuing withdrawal of treatment practice reflects a means of feeling in control of a situation (Shorter and Stayt, 2009). From previous clinical experience, nurses achieved this by removing unnecessary therapies and equipment from the patient's bed space, which in turn facilitated space for family vigilance. The nurses also collated the necessary paperwork for documentation, and supported the dying patient and family behind the privacy of the closed curtains around the patient's bed space. Closed curtains around the patient's bed space served as a symbolic protection mechanism where entrance was restricted. The strengths of Shorter and Stayt's phenomenological (2009) study lies in their conclusion that emotional disengagement from caring for the dying patient may have an impact on the quality of care for the dying patient and the family, due to the nurses' repeated exposure to death and grief. Curtis and Patrick (2001) suggest that discomfort with discussing death is universal and is not a problem unique to critical care nurses alone because it is rooted in society's denial of dying and death. Conversations pertinent to dying and death are sometimes viewed as socially unacceptable in modern society, where death may be perceived as a disease or an enemy instead as a part of life.

Bach *et al.* (2009) advocate that one of the most fundamental roles critical care nurses play in providing emotional support to families and patients is being present at the bedside, providing comfort, a caring touch and a listening ear. Vouzavali *et al.* (2011) aptly suggest that a need exists to allow critical care nurses the time to share and reflect on their stories and experiences through discourse, because meanings

may emerge with the possibility of growth, rather than experiencing a traumatic event. Vouzavali *et al.* (2011) continue by saying critical care nurses wish to be controlling probably due to the fact that they respond to critically ill patients' changing conditions, but they also learn and mature through their association with dying patients. Ciccarello (2003) supports the notion that nursing presence during withdrawal of treatment care is a simple but powerful intervention. In an attempt to overcome the dehumanising aspects of dying in a technological environment, nurses reconnect the patient with their family by the development of trust between nurses, doctors and the patient's family in an open and informative communication (Fridh *et al.*, 2009). The art of creating comfort and compassion in the midst of advanced technology during dying and death in the ICU has a direct impact on the memories that family and personnel take with them after this sad life event. Pattison (2011) concludes that where critical care nurses engage and are involved from the time the decision to withdraw treatment is confirmed until the death of the patient, it can be a potentially satisfying, albeit sad, experience.

3.5 Research question, aim and objectives

The research question for this study was 'What are critical care nurses' experiences following the decision to withdraw life-sustaining treatment from patients in a UK intensive care unit?' The aim of this study was to explore critical care nurses' experiences following the decision to withdraw treatment from patients in a British intensive care cultural setting through an ethnographic lens of enquiry. The research objectives for the study were:

- To explore critical care nurses' experiences following the decision to withdraw life-sustaining treatment from critically ill patients in the ICU.

- To investigate how nurses manage the process of withdrawing life-sustaining treatment from patients in the ICU.
- To explore how nurses' make sense of their experiences of withdrawing life-sustaining treatment from patients in the ICU in a nursing culture.

3.6 Summary

Deciding to withdraw life-sustaining treatment is taken after consultation with members of the critical care nursing and medical team, where a consensus is reached by the entire team involved in the management of the patient's care. However, prior to commencing withdrawal of treatment, the significance of the patient's poor prognostic factors must be explained and discussed with the family, allowing them time to come to terms with their impending loss.

The family is informed of the rationale behind the decision to withdraw treatment and should be in agreement with the decision. Within the UK, end-of-life decisions are usually made by the multi-disciplinary intensive care team as decision making remains one of the salient issues before end-of-life care is considered. Nurses thus play a key role in the decision making process. Nurses' seniority and experience regarding treatment withdrawal influences their input and contribution towards the decision making process.

A trusting and respectful relationship usually develops between the patient, nurse and family during the patient's critical illness journey in the ICU. Nurses bridge the gap between the patient and their family during withdrawal of treatment and help the family to reconnect with the dying patient. Creating an ambience of comfort and compassion in the midst of advanced technology during dying and death in the ICU has a direct impact on the memories that family will have for the rest of their lives.

Chapter 4: The research endeavour (planning the research)

4.1 Introduction

This chapter explains planning the first part of the research endeavour, namely planning the research. It includes a rationale for choosing an ethnographic stance for the study, ethical considerations and the reflexive self. Chapter 5 describes the second part of the research endeavour, which is doing the research.

Qualitative research was the overarching approach adopted for this study, using a lens of ethnography to delve into the intensive care nurses' experiences, world and culture. Interpretivism reflects a belief that the meaning of human experience is affected by the interpretation placed on it by individuals, based on previous experience and personal beliefs and that, therefore, those who have experiences are the most knowledgeable about them (Crookes and Davies, 2004). My intention was that this study would be interpreted and fashioned by the multiple views of both the participants and the researcher.

4.2 Situating the research in relation to the theoretical framework

I set out to explore the contribution of different ways of 'knowing' and types of knowledge relevant to nursing practice at the onset of this study. Nursing practice uses knowledge from different sources, namely tradition, intuition, experience, expertise and research (Crookes and Davies, 2004; Parahoo, 2014). This led to an awareness of the inseparable link between research and knowledge and the fact that the nature of this study was to create new knowledge in the field of critical care nursing.

The theoretical framework selected to situate the research stems from anthropological, nursing and sociological disciplines. In using this framework, I could question the sociological theories of awareness of dying (Glaser and Strauss, 1965)

and social death (Sudnow, 1967) as social processes in the context of the dying trajectory following treatment cessation in the ICU as experienced and managed by nurses. I employed a qualitative approach to explore critical care nurses' experiences following the decision to withdraw treatment from patients in a British intensive care cultural setting through an ethnographic lens of enquiry. It would involve collecting and interpreting data through a process of inductive reasoning.

Traditional debates exist about the differences between quantitative and qualitative research. Quantitative research can be described as the objective measurement and examination of concepts or variables by numerical and statistical procedures, where the researcher seeks to establish relationships between such variables by use of sophisticated mathematical techniques and computerised software (Polit and Beck, 2008). Quantitative research is aligned to the positivist paradigm and utilises a scientific method of enquiry by explaining the world in terms of quantification (Crookes and Davies, 2004). However, some clinical nursing phenomena may not be amenable to measurement, and require in-depth understanding and exploration of participants' thinking and behaviour obtained by adopting a qualitative research approach. Since the aim of this study was to explore nurses' experiences in the clinical practice of withdrawing treatment, the quantitative research approach would not offer any real depth of description and cultural exposure to the topic under study. Therefore it was deemed inappropriate and thus rejected. A quantitative research approach would be equally be unsuitable for this study because the research question for this study aimed to generate exploratory knowledge of what is not known about nurses' experiences of withdrawing treatment from patients in a British ICU.

In contrast to quantitative research, a qualitative approach explores the social world, which is not fixed or external, varies with time and place, and views human

behaviour by the shared meanings people hold rather than by universal laws (Polit and Beck, 2008). Qualitative research therefore encompasses a form of social enquiry that focuses on the way people interpret and make sense of their experiences and the world in which they live (Hammersley, 2004). Consequently, researchers often explore a phenomenon in the natural setting in order to gain an understanding of the complex world from the viewpoint of those who live in it. It is not possible for qualitative researchers to be objective and value free, as it is considered inappropriate for researchers to manipulate and control people and events as this alters the way they behave (Cresswell, 2009); qualitative researchers therefore study participants in their natural setting.

I chose the interpretivist paradigm for my study as it embodies the belief that people continuously make sense of the world around them, and that different people may have different interpretations of the same experience (Silverman, 2003). A paradigm is viewed as a set of basic beliefs that guide action by providing a worldview which shapes the way we interpret and understand our world (Denzin and Lincoln, 2011). Paradigms attempt to answer three sets of questions, namely epistemological, ontological and methodological:

Epistemology, or the theory of knowledge, is concerned with how we know what we know, what justifies us in believing what we do, and what standards of evidence we should use in seeking truths about the world and human experience. (Audi, 1998, p. 1).

Ontology in qualitative research is shaped and influenced by how the participants interpret and interact in their world and methodology with the methods and approaches that are used to generate knowledge (Silverman, 2003). Epistemology thus seeks to understand the relationship between a researcher and knowledge, whereas ontology seeks the nature of reality, and methodology concerns the methods and approaches that are employed to generate knowledge.

The epistemological and ontological assumptions for this study guided the chosen methodology of ethnography to address and answer the research question. The emphasis was on exploring a specific clinical practice whilst preserving the complex patterns of critical care nurses' behaviour following the decision to withdraw treatment from critically ill patients. This study would explore critical care nurses' experiences following the decision to withdraw life-sustaining treatment from critically ill patients in the ICU; investigate how nurses managed the practice of withdrawing treatment; and determine how the nurses made sense of their experiences. I anticipated reflexivity would be embedded throughout the study as I explored culturally derived and situated interpretations of a critical care nursing life world.

Ethnography was the methodological choice for this study due to an identified gap in the literature, and my intention was to explore the clinical practice of withdrawing treatment as managed by critical care nurses within the distinctive cultural setting of an intensive care unit. I realised that a phenomenological approach would also offer in-depth exploratory data; however, I was eager to explore the cultural patterns and behaviour of the participants with a specific emphasis on their cultural world. Phenomenology seeks to understand the subjective, lived experiences and perspectives of participants, with an emphasis on an individual's unique experience (Hammersley and Atkinson, 2007). However, by opting for ethnography, I would seek and explore the collective experiences of a specific cultural group, namely a group of critical care nurses. This would then exclude other qualitative methodologies. In addition, retrieved studies from the research review revealed that most of the qualitative approaches used in previous studies adopted phenomenological and survey methodological approaches. Ethnography explores how a social group eventually evolves a culture that guides its members' views of the world and structures their experience (Yamaguchi, 2004). Another reason why I chose to

conduct an ethnographic study was my eagerness to learn from the critical care nurses' cultural group, and to better understand their world. Having worked predominantly in a southern hemisphere country, I was interested in exploring the culture within a British ICU.

Crotty (1998) describes ethnography as an interpretive and reflexive process. Ethnography conveys a cultural description of a particular group in society, and Harper and Fontaine (2009) suggest ethnographic studies are highly influential in researching professional and clinical practice issues, especially in the discipline of nursing. A few authors, for example Seymour (2001), Philpin (2007), and McMillen (2008), have conducted ethnographic studies pertinent to the topic of nurses' involvement in end-of-life care in the ICU. However, these studies have not focused specifically on how the nurses conducted and managed the practice of withdrawing treatment, and on their experiences of accompanying the patient and family through the patient's dying journey as a result of treatment cessation. This ethnographic study relied on data collection in a British ICU exploring the behaviour of nurses and the influence of the culture in which they lived and worked. Therefore my study seeks to address this gap in knowledge by collecting and interpreting qualitative data to advance nursing practice through understanding how best to support nurses during this emotive and often fraught time in an intensive care environment.

An additional benefit of using ethnography was the capacity to deal with sensitive issues and the scope to make visible the practice of nurses' experiences of withdrawing treatment. What we do in our everyday working lives and the meanings behind our implicit, tacit actions are not always open to immediate interpretation or discovery (Harper and Fontaine, 2009). This view is further supported by Herbert (2000) who suggests social life is not always observable, and the meanings of objects and events are often revealed through practices, actions, cursory comments

and facial expressions. This, in essence, encompassed the rationale which informed the choice of ethnography for the study. By using an ethnographic approach for this research study, I would be able to focus on the descriptions of nurses' experiences, relationships and interpretations the nurses place upon these. One may argue that nursing research not only concerns finding answers, but also is about affording meaning to everyday lives by exploring clinical practice.

4.3 Ethnography

Ethnography has its origins in social anthropology and anthropologists such as Malinowski (1922), Boas (1928) and Mead (1935) searched for cultural patterns, behaviours and rules among 'exotic' peoples and tribes within primitive cultures (Hammersley and Atkinson, 2007). However, contemporary ethnography explores local cultures such as occupational and organisational groups in society. Ethnographic studies explore healthcare issues within clinical practice such as healthcare culture, institutions as a cultural backdrop and groups of professionals who form a cultural system. After reviewing the literature, the main influence for conducting an ethnographic study was my intention to gain an in-depth description and interpretation of cultural patterns and meanings within a critical care nursing group and culture. The emphasis would be on a specific clinical practice of withdrawing treatment and exploring a group of critical care nurses within their cultural world. I chose interpretive ethnography as I believe it would embrace a cultural perspective that involves multiple realities and the exploration of a group of nurses in a specific intensive care environment.

Nursing ethnographers often live with the participants during the working day, but spend their private lives away from the location where the study is being conducted (O'Reilly, 2009). The overarching approach of qualitative research was adopted for

this study using interpretive ethnography to explore the intensive care nursing world and culture which involved interpretation of the nurses' social world. An interpretive approach to the analysis of ethnographic data reflected the nurses' experiences of withdrawing treatment and the patient's journey of dying and death within the ICU setting.

Ethnographic studies are highly influential in researching professional and clinical practice issues, especially in the discipline of nursing as an interpretive and reflexive process (Crotty, 1998; Harper and Fontaine, 2009). Several authors have conducted ethnographic studies relevant to nurses' experiences and withdrawal of treatment in ICUs, namely Seymour (2000); Badger *et al.* (2009); Philpin (2006); Costello (2006) and McMillen (2008). I anticipated that my study would collect qualitative data which could further develop the body of knowledge in this under-researched area of critical care nursing practice. Coffey (1999) suggests ethnographic writing places the self at the heart of the analysis and can be viewed as a mechanism for establishing authenticity. Furthermore, Coffey (1999) views the reflexive trend in ethnography over the past decade as giving rise to the use of personal narrative as a reliable mode of expressing findings from the field. Reflexivity and the knowledge gained from writing this ethnography proved to be an enriching experience for me as a novice researcher.

Methods which were employed for this ethnographic study included participant observation, semi-structured interviews with two vignettes, naturally occurring talk and field notes.

I believe Brewer aptly captures the essence of ethnography by offering this definition:

[Ethnography is] the study of people in naturally occurring settings or 'fields' by methods of data collection which capture their ordinary activities, involving the researcher participating directly in the setting, if not also the activities, in order to collect data in a systematic manner

but without meaning being imposed on them externally (Brewer, 2005, p.189).

As Herbert (2000) states, social life is not always observable and the meanings of objects and events are often revealed through practices, actions, cursory comments and facial expressions. This ethnographic study aims to render the familiar strange, because ethnographic research has the capacity to embrace and explore a culture we feel we already know (Guba and Lincoln, 1985). The concept of meaning within this culture is associated with the specific activities conducted by the nurses and it is through these activities that the group expresses and makes appropriate to the ICU setting (Alasuutari, 2000). Ethnography therefore provides a pathway into understanding the cultural differences of the critical care nurses as human beings and, as Spradley (1979) suggests, the widespread realisation that cultural diversity is a great gift bestowed on people.

The goal of ethnography is the production of knowledge and, as Hammersley and Atkinson (2007) imply, the philosophical, ethical and methodological strands of ethnography are often intertwined, reflecting on and understanding everyday events using different techniques. As both a process and a product, the term applies to a methodology and to the written account of a particular ethnographic study (Savage, 1995).

In traditional ethnographic studies the researcher is immersed in the culture of the group to be studied by living and working in their midst or spending significant time with them, in order to see the world from the participants' perspective (Hammersley and Atkinson, 2007). The main instrument of data collection is the researcher and data is collected from as many sources as possible. Fieldwork is accomplished as the researcher spends time in the company of the participants being studied. Ethnographers participate in people's lives, observe what is happening, listening and

asking, and collect whatever data is available to highlight issues of importance relevant to the research (Hammersley and Atkinson, 2007).

This study documents the intricate details of a particular life event and scenario in the ICU to discover the ways participants categorise, code and define their own experiences. It was also concerned with identifying how the social and cultural construction of withdrawing treatment from critically ill patients by nurses shaped an understanding of how the nurses in the ICU participated, worked, communicated and related in ways which involved elements of passionate and tacit knowing not readily accessible at an analytical level (Henderson, 2005).

I believe ethnography is an appropriate choice for this research study as it describes how this cultural group of critical care nurses work. It also explores beliefs, language, and human and physical behaviour of the group within the realms of clinical practice against the social, economic and political backcloth of an ICU within a NHS hospital. The focus is on nurses in an ICU and the cultural environment of this specialty. As a group, the intensive care nurses have worked together and shared a common language with cultural behaviours, attitudes and roles merged into a discernible pattern. My intention is to produce a theoretical and analytical descriptive study illuminating the reality of the dying trajectory and patient death as experienced by nurses following treatment cessation, and simultaneously reveal features of human social life. I envisage this study will provide insight into the ways in which I (the self) and multiple other social actors actually experience clinical practice through a cultural immersion within the intensive care setting. An ethnographer should therefore maintain some sense of an external, objective framework to provide what Guba and Lincoln (1985, p. 198) refer to as 'emic validity'. This emic validity involved understanding the participants' perspectives through rigorous and iterative

observations, interviewing, and witnessing scenarios where treatment was withdrawn.

Additionally, the research enquiry may offer an understanding of nurse involvement, interpretation and experiences during the patient's end-of-life care. Cultural beliefs influence reality construction and an intrinsic relationship exists between an individual's behaviour, attitudes, external structures, and socio-cultural and political issues (McLaughlin, 2006). The interpretivist stance for this ethnography focuses on understanding meaning of action from the nurses' perspective and explanation of observed practices through a system of gathering, verifying and systematising information. Language is therefore more than a means of communication about reality: it is in fact a tool for constructing reality (Spradley, 1979; Crotty, 1998).

In the field, people make sense of their world by attempting to interpret themselves and others as revealed through emerging, situated acts on the social scene (Atkinson *et al.*, 2010). Ethnographers remain immersed in this knowledge during the fieldwork. Although ethnography is a complex activity drawing on a range of epistemological positions and methods, and often demanding different modes of evaluation (Savage, 1995), it remains useful in understanding critical care nurses' experiences of withdrawing treatment in their cultural world of a British ICU. Adopting an ethnographic approach is itself theoretical, because the ethnographic literature articulates how a researcher thinks the social world functions and how to access knowledge of this world under study (Silverman, 2003). I will generate and interpret data from this ethnographic perspective throughout the study.

Written accounts of this study will be the product of the intermingling of my role as a researcher and the research participants in a certain time and space within a specific intensive care unit (Mulhall, 1997; Coffey, 1999). I perceive thick description

going beyond mere fact; it presents detail, context, emotion, and a web of social relationships that join people in a group to one another. My intention for using thick description is to describe how withdrawal of treatment evokes the participants' emotionality and self-feelings, and the significance of the events that led up to withdrawal of treatment and the participants' experiences. In thick description, the voices, feelings, actions and meanings of interacting individuals in a group are heard (Denzin, 1989, p. 83).

Emotions, thoughts and perceptions that the participants experience will be presented through the medium of thick description as described by Geertz (1973). Thick description should reveal meanings and interpretations of the critical care nurses from within their culture, and is explicit in the detailed patterns of their cultural and social relationships within the ICU. Ethnographic interpretation therefore cannot be separated from time, place and events, and is based on the meaning that actions and events have for the critical care nurses within a cultural context (Holloway and Wheeler, 2010). Description and analysis are rooted in reality whereby I will reflect on the nurses' social events and conduct (Silverman, 2003). My intention in using a form of thick description is to offer the reader a sense of the emotions, thoughts and perceptions that the participants experienced. Thick description attempts to remain theoretical and analytical by focusing on the patterns and traits of the social life in the critical care nursing culture (Holloway and Wheeler, 2010), and therefore the participants' behaviour patterns become embedded within the thick description. Geertz (1997) points out that thick description in ethnography refers to interpretation and synthesis by the researcher, and is a representation of interpretivism. Throughout the data collection process, I will be a part of the culture being studied and will be exposed to the nuances of everyday life within this specific culture. Ethnography therefore affords a high degree of reflexivity because the researcher

acknowledges how their particular cultural setting, who they are, and their own values and beliefs, shape the conduct of the study and interpretation of data (Polit & Beck, 2008).

4.4 Ethical considerations

Prior to commencement of the study ethical approval was obtained from the University of Salford Research Governance and Ethics Committee and the National Research Ethics Service (NRES), and ethical approval and an honorary contract were obtained from the Research and Governance Department of the NHS Trust where the study was conducted. As a registered nurse practitioner, I also adhered to the Nursing and Midwifery Council (2008) *Standards of conduct, performance and ethics for nurses and midwives*.

The ethical starting point of this study was to adhere to the ethical principles of beneficence and non-maleficence during the study whilst maintaining participant confidentiality at all times. Each participant's dignity, rights, safety and well-being were respected throughout the study. All material used during the study was stored safely and treated with the same respect. Participants' identities remained anonymous as a fictitious name was assigned to each participant to maintain confidentiality. The other ethical principles of autonomy, confidentiality, informed consent and data protection (according to the Data Protection Act of 1998) were adhered to throughout the study. Informed consent was obtained from the participants through a process of ongoing negotiation for both the observation period and interviews. A copy of the consent form for observation and the interview are attached as Appendix G.

The Department of Health (2001a) stresses that informed consent is at the heart of ethical research. Once the consent form had been signed by the participant, a

copy was given to the participant and a copy was kept by the researcher. For the consent to be valid, the participant must be competent to give consent, must understand what they are consenting to, and consent should be voluntary and not coerced (Silverman, 2003). A copy of the invitation letter sent to all interested potential participants may be found in Appendix E.

Parahoo (2014) suggests that the researcher should ensure that the participants understand the potential risks and benefits of participating in a study. This information was provided in the format of the participant information sheet (please refer to Appendix F). The participant information sheet included all the aspects relevant to the study, and each participant was given a copy and the opportunity to ask questions. The right to refusal or withdrawal from the study was clearly explained to each participant. Participants were informed about their right to participate and were provided with information that was free from coercion. Anxiety and distress, exploitation, misrepresentation and identification of the participant in published papers are potential risks to research participants associated with qualitative research (Polit and Beck, 2008). Permission for including participants' responses in subsequent publications was obtained through the consent form.

As a researcher I was aware that the nature of qualitative research seemed harmless and involved listening and talking to participants. However, due to the sensitive nature of the topic supportive mechanisms were in place if in the event a participant might become distressed during an interview or observation. Clinical supervision by the intensive care matron and the Trust's counselling services were readily available if needed. At all times during the study, the rights, well-being and safety of participants were a priority. As an ethical response to ensure participant safety, I employed two vignettes during the interviews in an attempt to protect participants when exploring the sensitive topic of withdrawing treatment. The two

vignettes were discussed at the beginning of the interview, followed by the participants' own experience of withdrawing treatment. In my role as a researcher, I was acutely aware that during the interviews and observation, ethical and moral dimensions of care such as withdrawal of treatment could ignite emotive responses in the participants due to the fraught and fragile topic, which often presents as a dilemma. During the observation period and the interviews I treated and respected each participant as an individual, and relied heavily on my sensitivity and communication skills in building a trusting relationship between researcher and participants. Throughout the data collection I felt extremely privileged and appreciative that the participants trusted me and were prepared to spontaneously share their experiences with me. I believe the interview experience may have been cathartic for some participants although this was not the purpose of the interviews.

4.5 The reflexive self

At the onset of the study, as an ethnographer and nurse practitioner, I realised that reflexivity would become an important part of my research journey, learning and transformation as a researcher. To become a reflexive researcher, Holloway and Wheeler (2010) believe that the researcher should critically reflect on their own preconceptions, and examine their relationships with the participants and their own reactions to what the participants say and do. As the main tool of the research, as a researcher I was aware that I would be a part of the topic to be studied which necessitated a self-reflection of my feelings, actions and conflicts experienced during the study. The study became more credible and dependable as I adopted a self-critical perspective towards the research and my own role, relationships and assumptions.

Finley and Gough (2003) suggest that a function of reflexivity is to assist situating the researcher within the study. Etherington (2004) explains the notion of reflexivity as being aware of our personal responses and being able to make choices about how to use them. In addition, researchers should be aware of the personal, social and cultural contexts in which they live and work, so as to understand how this impacts on the ways that the researcher interprets the world (Etherington, 2004). Reflexivity within this ethnography was viewed as an on-going conversation or story as participants share their experiences of living the moment in a certain time and place. Wilkinson (1988) suggests personal reflexivity helps the researcher make visible their individuality and its effects on the research process. As a researcher my motivations, interests and attitudes which could be introduced in the study may be interpreted as bias. However, it could be argued that bias is apparent in any style of research. I have chosen the qualitative research approach for my study which according to Finley and Gough (2003) recognises the personal dimension to research, yet views it as enriching and informative.

The exploration of culturally derived interpretations of nurses' experiences within the intensive care social life world will necessitate adopting a reflexive stance, and drawing on the constructs of the participants through the application of the emic and etic perspectives. Murchison (2010) suggests a good deal of the ethnographer's work is involved in the emic (insider) and etic (outsider) perspectives, between what people say and what they do, and what has been described previously and what is encountered in the course of the research. The emic approach will attempt to understand components of the nursing cultural system from the perspective of the nurses being studied, whereas the etic approach analyses a cultural system with research paradigms brought by the researcher from outside of that system (Pelto and Pelto, 1978). The emic perspective is critical to the ethnographer's primary goal of

learning about the world of the critical care nurses' community of practice: as Malinowski (1992, p. 25) stated the goal of ethnography is: ...to grasp the native's point of view...to realise his vision of the world.

Guba and Lincoln (1985) suggest complementing the emic with an etic viewpoint is important for understanding all aspects of a human group because the attributes of the culture include dichotomies such as the ideal versus the real and the tacit versus the explicit. Emic and etic viewpoints are further discussed in chapter 5. Altheide and Johnson (1994) suggest reflexivity is the best prescription for enhancing interpretive validity. This emic validity will involve understanding from the perspectives of the participants through rigorous and iterative observations and interviews during the study. Therefore, the researcher's reflexivity becomes infused within the thesis in an attempt to achieve plausibility. Coffey (1999) suggests reflexivity is an ongoing conversation about experience while simultaneously living the moment, and Mulhall (1997) postulates that all research written accounts are really cultural artefacts, and the product of the intermingling of the researcher and the research participants in a certain time and space. Throughout the study, I continually reflected on both my experiences as a researcher and my previous experiences as a practitioner. I recall that when I commenced the observation phase of the study it felt really strange to view the intensive care milieu as an observer. I often had to try to be naïve in viewing what I observed through an unfamiliar lens. However, positioning myself in a corner in the ICU or at the nurses' station seemed to somehow help me distance myself from the practitioner role. Reflexivity may be a means to bridge the gap between research and practice, and is ongoing through data collection, analysis, interpretation and writing up (Holloway and Wheeler, 2010; Etherington, 2004).

Reflection enabled me as a researcher to explore, learn and understand what I could bring to my research and how I viewed the participants' world through an

ethnographic lens (Mansfield, 2006). A personal journal which was separate from my field notes captured my research journey of discovery, reflection and reflexivity from the onset. Writing this journal created increased self-awareness, cultural consciousness and ownership of my personal perspectives which led to further self-exploration and self-understanding throughout the research journey. At a deeper level of reflexivity, I experienced a belief in others' voices and their right to participate and contribute, and the role of human experience as a source of learning and knowledge (Mansfield, 2006). Through practising reflexivity I also experienced a sense of empowerment and influence in giving voice to my research.

4.6 Summary

This chapter has described how I arrived at choosing ethnography as the most appropriate research design in answering the research enquiry within a qualitative perspective. I decided that the qualitative research approach would afford the opportunity to interpret what is seen, heard and understood during the study, yet also incorporate my own previous experience, context and prior understandings. Ethical considerations and the reflexive self were discussed in this chapter. Chapter 5 will discuss doing the research, which shapes the second part of the research endeavour.

Chapter 5: The research endeavour (doing the research)

5.1 Introduction

In this chapter I discuss the process of doing the research, applying an ethnographic approach to data collection. Ricoeur's analytical framework of data analysis, emergent themes, personal reflection on transcribing, rigour and authenticity are also discussed. The data collection methods included observation, interviews and witnessed scenarios of withdrawal of treatment in the intensive care unit.

5.2 Participants

5.2.1 Selection of participants and sampling strategy

The participants were registered nurses who worked in the ICU and who voluntarily agreed to be observed and interviewed for this study. The participants were purposefully invited because they could make a unique contribution and offer meaningful insight to the study due to their professional experience and status. Inclusion criteria stipulated each participant was to have worked for longer than one year in the ICU and had experienced withdrawing treatment in an intensive care clinical setting. It was imperative that the participants had insight and knowledge into the withdrawal of treatment practice.

The sample was purposive and the participants within the study included Band 5, 6 and 7 nurses working in a large 20-bed ICU in a NHS Foundation Trust hospital in the North West of England. The sample included registered critical care nurses with experience of withdrawing treatment in an intensive care unit. Qualitative research is one of discovery rather than testing a hypothesis so, according to Glaser and Strauss (1967) and Miles and Huberman (1994), a small sample size is acceptable, especially when using semi-structured interviews. No guidelines exist regarding sample sizes in qualitative research. However, research texts suggest 6 to 8

participants are needed when the sample consists of a homogeneous group, but sample size does not necessarily determine the importance of the study or the quality of the data (Hammersley and Atkinson, 2007).

In qualitative research a sample consists of sampling units of people, time or setting which necessitates selecting the individuals (who to sample), the time and context (what to sample) and the place (where to sample) because people and places must be available and accessible (Silverman, 2003; Holloway and Wheeler, 2010). Initially there were potentially 16 interested, self-selected participants, but due to availability and accessibility issues 8 participants were finally interviewed. One participant experienced a family bereavement prior to the interview so was not selected. The sample selection represented a cross-section of the nursing population in the ICU. Due to the large nursing complement including time and resource constraints it was not possible to interview all the nurses, so a sample was selected to represent the total nursing population (Hammersley and Atkinson, 2007).

Purposive sampling implies that the participants are hand-picked: the researcher already knows something about the specific people and event, and then deliberately selects the participants because they are likely to produce the most valuable data and best information (Denscombe, 2006). The author goes on to suggest that purposive sampling is advantageous as it allows the researcher to home in on participants critical for the research and illuminate the research enquiry (Denscombe, 2006).

The eight participants who volunteered for the interviews were selected from a sampling frame of Band 5, 6 and 7 nurses working in the ICU because they had knowledge and experience of withdrawing treatment from critically ill patients in an ICU. The participant sample conveniently consisted of 4 male and 4 female participants. My intention was to select a few participants from each nursing Band to

obtain representatives of the total nursing population. One difficulty encountered during the recruitment of participants was as a result of the day duty shift patterns. Day shifts in this particular ICU involved a long day shift (07h45–20h15), so this would necessitate nurses relying on their colleagues to care for their patient while they were being interviewed. As a result, four participants agreed to be interviewed in their off duty time which was an extremely generous gesture and very much appreciated. Two participants were interviewed in the early hours of a Sunday morning whilst on a night duty shift and two participants were interviewed whilst on day duty shifts. On two occasions, the ICU was very busy and a participant was caring for a haemodynamically labile patient, so the planned interview was rescheduled for another date. On another occasion, I had arrived at the hospital for the interview only to find the intensive care unit was a hive of activity due to several medical crises encountered during the night shift. The interview was rescheduled for another night as the participant was working permanent night duty.

Denscombe (2006) advocates that a sampling frame should include an objective list of the population from which the researcher can make his or her selections. The subsequent participants who volunteered to be interviewed were from different nursing Bands and genders. More than eight nurses volunteered to be interviewed which necessitated choosing the participants as the opportunity arose for both observation and interviewing. The nurses who volunteered to be interviewed were given time to read through the participant information sheet and ask questions prior to signing the consent sheet. Written consent was obtained for each day of observation to ensure transparency, so that the personnel were aware that a researcher was in the intensive care environment. I was pleasantly surprised that 16 nurses volunteered to be participants for the interviews and, debarring one nurse,

every nurse I approached during the observation period consented and agreed to be observed.

5.2.2 Participant demographics

Eight intensive care nurses who fulfilled the inclusion criteria for the study were interviewed. The inclusion criteria stipulated that the nurses were to be qualified nurses with a minimum of one year of intensive care experience and had experience in withdrawing treatment in critically ill patients. Initially 16 potential participants volunteered to be interviewed, but due to unforeseen circumstances – for instance, changing jobs, ill health, maternity leave and unavailability due to shift patterns – 8 participants were finally selected. I intentionally chose four female and four male participants comprising three Band 5 nurses, three Band 6 nurses and two Band 7 nurses as a representation of the total nursing population in the ICU. All participants were given fictitious names to maintain confidentiality and anonymity. The average age of the participants was 38.5 years and all the participants were of British nationality. Fifty percent of the participants actively practised a religion and the other fifty percent of participants were self-confessed atheists. The participants average years of intensive care experience was 10.8 years. Of the six participants who were interviewed during the day, five participants willingly gave up their off duty time to be interviewed. One participant was on a day duty shift when interviewed. The remaining two interviews were conducted in the early hours of the morning over a weekend to accommodate the participants who were on night duty. It was a privilege to listen to and share the participants' stories during the interviews, and at times I felt the interviews were cathartic for the participants.

Table 1 below represents the demographics of the nurses interviewed.

Table 1: Demographics of participants interviewed during the study

Fictitious name	Band	Gender and age	Nationality	Years of experience
Abbi	5	female, 30	British	3 years in ICU
Efa	6	female, 48	British	16 years in ICU
Jethro	7	male, 42	British	18 years in ICU
Ziggy	6	male, 46	British	8 years in ICU, 17 years in ward areas and community
Uriah	7	male, 54	British	25 years in ICU
Dylan	5	male, 25	British	4.5 years in ICU
Ardelle	6	female, 37	British	12 years in ICU, 9 years in medical and surgical wards
Skye	5	female, 27	British	8.5 years in ICU

5.3 Data collection

As a researcher, I was immersed in the daily lives of the participants by data collection through observation and interviews and the analysis of the data. I was therefore the principal data collection tool and drew on the data to construct a narrative and written text of the ethnography. Polit & Beck (2008) state that the concept of the researcher as an instrument describes the significant role ethnographers play in analysing and interpreting a cultural phenomenon. I conducted the ethnographic study by exploring the intensive care culture, observed, interviewed and listened to the nurses who worked in the ICU, and produced a written account of the ethnographic text.

The data were collected and collated as the study unfolded as the product of an interpretive process. My researcher/practitioner perspective played a significant role in the production and interpretation of the data collected, and inevitably formed an integral part of the data analysis (Denscombe, 2006). Data collection involved an extended period of observation in the field within the ICU where I became immersed in the day-to-day lives of critical care nurses during their routine, emergency and

withdrawal of treatment practices. In addition, I witnessed six scenarios where treatment was withdrawn from critically ill patients and conducted eight interviews. Coffey (1999) suggests a strength of ethnography research is the real involvement of the fieldworker in the cultural setting being studied and a weakness is not the possibility of total immersion, but rather the failure to acknowledge and critically engage with the range of possibilities of position, place and identity.

5.3.1 Being in the field

Spradley (1979) describes ethnographic fieldwork as an open-ended, iterative and reflexive process. Cresswell (2007) points out that gathering information where the participants work is referred to as fieldwork. I positioned myself as a researcher within the intensive care environment amongst the nurses and gathered data from their working lives. Reflexivity is a defining feature of qualitative research where the researcher is a central figure who actively constructs the collection, selection and interpretation of data (Finley & Gough, 2003). Reflexivity was embedded throughout the study. Coffey (1999) believes that ethnographers cultivate strangeness and distance in order to gain insight and understanding of the cultural setting while simultaneously experiencing personal growth through reflexivity. From the outset, I realised that I would need to develop this aspect of reflexivity. I found it challenging to manage my stance as an expert practitioner, yet maintain a degree of 'strangeness' as an outsider to the nurses' world of intensive care practice. Coffey (1999) further suggests ethnographers should contend with a tension between strangeness and over-identification during their study. However, this tension actually helped me as a researcher to create a cultural picture of the nurses I observed and interviewed which included their (emic) perspectives as well as my own (etic) perspective. Atkinson (1997) explains one cannot make serious sociological sense of the culture studied if

one remains ignorant of what nurses actually do. I therefore continually poised on the interface between the familiar and the strange during the fieldwork. My previous experiences as a practitioner opened up the 'familiar' although I did try to view events through a naïve lens. However, having not worked in this particular ICU did facilitate opportunities to observe the 'strange' during the fieldwork.

Once ethical approval was obtained I arranged appointments with the gatekeepers – namely the charge nurses, intensive care matron, intensive care practice education facilitator and director of the ICU – to fully explain my intended research and gain access to the field. Fetterman *et al.* (2003) suggest ethnographers may experience difficulties and challenges in gaining access to the field and often encounter a rude awakening when seeking this access. That said, a factor pertaining to my access preparation was the fact that the setting was known to me as a link lecturer within my academic role at the university where I was employed. However, I had never practised in the ICU where the fieldwork was conducted so as a consequence needed to be mindful of any challenges relevant to access. I displayed a poster and a copy of the participant information sheet on the notice boards of the staff tearoom and the family/relatives waiting room, with information about the study and notification that a researcher would be in the midst of the ICU. The Director of the ICU furnished a consent document to specify his approval that I was to conduct my research in the ICU. A copy was included in the NHS Trust ethical approval documents.

I spent a large proportion of my fieldwork positioned at the nurses' station as it was the most practical location in the ICU where I could have a panoramic view of all the activities happening around each patient's bed space. Occasionally, I would retreat to a quiet corner or empty bed space in the ICU and quietly observe, listen and savour the ambience of the ICU. At times I remember closing my eyes and

listening intently to the unseen activities and sounds around me, relying on my senses to guide my interpretation of the surrounding scene. Maintaining an invisible presence was important at times, especially during the occasions when I observed withdrawal of treatment scenarios from the time the decision was taken until after the death of the patient. As I commenced my fieldwork in the ICU, I was allowed to wear the blue scrubs which afforded me the privileged position of being part of the intensive care team, permitting me access to their world from the periphery. With time and as my observation continued, the personnel became more relaxed with my presence and started sharing their intensive care life world with me. The ICU clerical worker befriended me and soon became one of my primary gatekeepers during the study. She was exceptionally astute and knowledgeable in all issues relevant to the general running of the ICU, aspects of patient enquiry, medical and nursing issues and patient documentation. The critical care practice development facilitator and I were acquainted as a result of my link lecturer role and our mutual attendance at the regional critical care network meetings. He also became an important and helpful gatekeeper during my time in the ICU, together with the charge nurses on the different shifts who often would discuss organisational issues and the business of the ICU with me during a lunch break. These gatekeepers were helpful because they were interested in my research and there appeared to be a strong research ethos in this ICU. I learned that several personnel were conducting research projects, namely a doctor, the transplant co-ordinator and two nurses who were engaged in the dissertation phase of their Advanced Practice degree. At no time did the gatekeepers or I try to force or coerce any nurse to participate in my study. I was actually pleasantly surprised at the interest shown towards the topic and the research project.

As a researcher, throughout the fieldwork I searched for comprehensive information and data were collected in the 'real-life' world of an intensive care unit on

a prompt and regular basis. Fieldwork thus identifies observation as an empirical method for data collection according to Denscombe (2006), and Coffey (1999) describes the experience of fieldwork as a personal journey of discovery. The fieldwork involved a process whereby I came to understand the intensive care culture, and the ethnographic text explored how the culture was communicated and portrayed. Whilst conducting the fieldwork and observing events as they normally unfolded, I attempted to minimise the extent to which my presence might alter or influence the scenarios under study by adopting an inconspicuous location and unassuming stance in the clinical environment. Occasionally nurses would speak to me as if I was working with them which necessitated acting as if I was an outsider to the intensive care environment. I had to consciously remind myself that in my researcher role everything which I observed was interpreted as unfamiliar and strange. This did, however, prove to be difficult at times because a few staff members recognised me as an academic. Several students, past and present, also worked and were on placement in the ICU. The staff would come over to greet me and enquire about my research or ask if I was working in the ICU. I overcame these interruptions by documenting them in my field notes, and noted the time and reason for the interruptions in my field notes as it did temporarily distract me from my observation.

The ethnography unfolded as the fieldwork progressed into an intensive caring scene interwoven with nursing activities, behaviour patterns and discourse. Although I was familiar with an intensive care environment from previous experience as a critical care nurse, my researcher role somehow helped me to view things from a different perspective, because in essence I was a stranger to this particular ICU. I acknowledge the study brought its own challenges. Time to collect the data proved to be extensive as it involved prolonged periods in the ICU, and as a researcher I soon realised the danger of losing focus and 'going native' within the research. My

researcher responsibilities included conducting the study in a sensitive, respectful manner that would be acceptable to the participants I interviewed and observed during the fieldwork whilst I resided in their life world. Savage (1995) argues the strength of ethnography is that it gives voice to individual experience and the researcher actually learns from people during their immersion in the field. The self as a characteristic of the researcher role emerged during the observations by listening to the nurses sharing their experiences in their daily activities. Coffey (1999) suggests the overt positioning of the researcher self is an intrinsic part of the fieldwork and the study, and the challenge lies in the progression from an ignorant stranger to a wise scholar almost treading a path towards self-enlightenment and personal growth. I made a concerted effort to adopt a sense of naivety and also at times distance myself in order to gain an understanding into the cultural setting which lent itself to my own personal growth. Initially I found it difficult to separate myself from the intensive care nursing culture and although the intensive care unit layout was unfamiliar, the reality of the intensive caring milieu felt like 'being back home'. I believe I gained meaningful insight relevant to the intensive care milieu by sometimes acting like a stranger within the setting. However, with time this aspect of estrangement and pretending to be naïve became more comfortable and enabled me to view things in a different light.

The intensive care team kindly accepted me into their social circle, enabling me to feel integrated into the team by being in the field, sharing their successes and sadness as I was allowed to come and go as I pleased. I shared their life world and developed good friendships and rapport with most medical and nursing staff, and unintentionally even some family members. The key informants during the study were the ICU clerk, practice education facilitator and charge nurses who became my access contacts within the formal and informal activities of the intensive care culture

and the subsequent gatekeepers of the study. I was told the personnel initially thought I was conducting a 'time and study' project on behalf of the Trust. However, once informed, the intensive care team readily accepted my researcher role and the longer I spent conducting my observations, the more relaxed personnel appeared. After the day's observation, whilst driving home, I would reflect back on the day and often found myself reflecting on my fieldwork during the shift. I recall one particular day that I witnessed the simultaneous withdrawal of treatment from two patients in the ICU. The decision to withdraw treatment took place after the ICU round and by the end of the shift the intensive care journey of two patients had ended. Two families returned home filled with grief and mourning. The day's events induced a feeling of *déjà vu*, a similar sadness I remember experiencing as a critical care nurse when patients I cared for underwent treatment cessation.

5.3.2 Field notes

Fetterman (1989) explains the notion that ethnographers begin with biases and preconceived ideas about how people behave and what they think. However, controlled biases can focus the research, whereas uncontrolled biases can undermine the quality of the research according to Fetterman (1989). I was acutely aware that my previous experience as a nurse practitioner could be perceived as a bias, and would need to be controlled and tempered so as not to interfere with the research. This process of collecting field notes involves an emergent discovery and recording of what is being observed and experienced by the ethnographer (Hammersley and Atkinson, 2007).

After a while in the clinical setting, I felt more comfortable adopting the researcher stance and distancing myself from a practitioner role. Adopting and positioning myself as a researcher in a participant observation stance certainly helped to achieve

this. Coffey (1999) suggests ethnographers collect and write field notes which embrace the personal and describe places, people and events. These field notes are also used for textual space for the recording of the researcher's emotions and personal experiences, and often the researcher keeps a separate set of notes for descriptive and also for personal use. Therefore field notes serve the purpose of documenting the researcher's personal progress, journey and diary (Coffey, 1999).

I compiled an observation journal based on the literature review conducted, as a guide to identify salient aspects worthy of inclusion, significance and relevance. The types of events and behaviour to be recorded were based on the frequency of events, events at a given moment in time, duration of events and sample of participants observed during the event. Each page of the journal was divided into two sections. One section captured the journal date, time and event, and a corresponding section described the memoing of what occurred and the interpretation of the event. In the journal I logged overt and observable behaviour which I considered to be obvious, relevant, precise and easy to capture in a clear and accurate manner. The recording of field notes also enhanced my reflexivity as a researcher, where in addition to my observations in the practice setting, I also recorded my reactions and feelings to what I observed and experienced.

A Gantt chart was compiled to represent the time framework which was spent in observation and conducting interviews in the field. Fieldwork was conducted during day duty shifts between 07h45-20h15 as the decision to withdraw treatment in the patient was usually confirmed during the morning ICU round and conducted soon thereafter, except in exceptional circumstances such as family members who live abroad. Fieldwork was conducted during the week and over weekends and totalled 144 hours. Coffey (1999) states that the observation role facilitates a strong position to deal with the meaning of actions from the participants' point of view, and allows the

researcher to place greater emphasis on depth, thus producing data which reflects the detail, subtleties, complexity and interconnectedness of the social world investigated. Hammersley and Atkinson (2007) suggest the fieldwork identifies issues and problems which participants regard as crucial, hence highlighting the importance of their views, beliefs and experiences.

5.3.3 Observation

Van Maanen (1998) describes how fieldwork requires the researcher to share the environment, problems, background, language, rituals and social relations with a specific group of people on a first-hand basis. In my role as a researcher I became a passive participant in the setting and culture of the intensive care world I was researching. However, my participant observer role implied that as a researcher I was first and foremost seen as an observer who was not actively engaged in the nursing activities or direct patient care of the participants I studied. It soon became evident to the personnel that I was an observer as I did not conduct any nursing care so was not 'hands on'. I became a part of their daily lives, openly recognised as a researcher, observing events as they unfolded, listening to what was being said and 'being there' within the intensive care setting. Denscombe (2006) suggests observation as a method may be advantageous as the main instrument in the research, as the researcher 'self' and the naturalness of the setting is retained. The author goes on to say that observation provides rich insights into social processes and complex realities, the data collected is context sensitive and holistic, and the participants' meanings are represented (Denscombe, 2006).

My intention to be openly identified as a researcher was to facilitate gaining informed consent from all the participants who were on duty every time I conducted my observation. This necessitated obtaining informed consent from the nurse who I

would observe, the charge nurse of the particular shift and the consultant in charge of the ICU for the particular day. I additionally obtained informed consent from each nurse I directly unintentionally observed during the witnessed withdrawal of treatment scenarios during the observation phase of the study. If a particular nurse waived consent on a particular day, their contribution was not observed nor represented in the field notes for that particular day. However, this only occurred once during the observation period. I observed patients unintentionally during the observation phase and during the witnessed scenarios.

The rationale for adopting this participant observation role but with 'no hands on' care during the study was twofold. Firstly, it prevented the tension which may have arisen between my researcher and clinical practitioner roles, thus preventing a dichotomy situation between the two roles from developing. Secondly, as a nurse with previous clinical experience within the intensive care milieu I was acutely aware that there exists an intimate and respectful bonding and trusting relationship between the family, the patient and the designated nurse caring for the dying patient during withdrawal of treatment. Active participation as a researcher during this fraught and fragile time may have been perceived as an invasion of privacy and disrespectful from both a personal and humanistic perspective. Prior to applying for ethical approval, a brief meeting was conducted with the intensive care matron, the practice education facilitator and senior nursing staff to discuss the intended research study. My intention for arranging this meeting was that it served as a courteous gesture as a researcher and facilitated access into the field.

During the observation, my researcher role wavered between the visible and invisible. This concept of the visible and invisible researcher role is described by Turnbull *et al.* (2005) who conducted an ethnographic study from the perspective of an outsider on the life world of ICU. The visible stance involved gaining consent on a

daily basis, being in the ICU, writing notes, responding and looking interested. Initially doctors appeared dubious of my presence, but later on appeared relaxed with my presence after the charge nurse informed them that I was a researcher. Some of the doctors engaged in lengthy conversations relevant to the topic under study and the importance of nursing research in the intensive care environment. It was apparent that the busier the ICU and the longer I conducted observations in the field, the more invisible my presence became in the personnel's intensive care world. As my fieldwork progressed, the nurses and doctors appeared more accepting and comfortable with my presence in the ICU. There were a few occasions during the fieldwork that both senior and junior nurses would unintentionally interrupt my observation by engaging in friendly conversations which involved how well or bad their day was going. This interruption was then documented and indicated as an interruption in the field notes. One of the domestic staff came up to me and asked what I was doing. After explaining my study, she asked me to please include the fact in my story that she was so proud to be part of this ICU as they were such 'caring' people. I promised her I would include her comment and immediately documented her contribution in my field notes. As a research method, observation demanded considerable time in the field and a climate where trust was gained, rapport established and insights were fostered.

I applied the emic and etic perspectives during the observations. This necessitated an understanding of the emic perspective, the insider's perceptions and accounts of reality which helped to uncover knowledge of the reasons why nurses acted as they did, and offered explanations from the nurses' point of view. The etic perspective was based on what was directly observable, and necessitated moving back and forth from the nurses' reality to what I as a researcher thought was important. By using these perspectives I anticipated this would provide insight into

the ways in which the self and others actually experienced the world of intensive care nursing practice during withdrawal of treatment. Although observations and interviews go hand in hand, the observations served as a starting point for the interviews (Parahoo, 2006).

5.3.4 Interviews

In addition to participant observation, semi-structured interviews were also used as a method of data collection during the study. I chose semi-structured interviews to obtain in-depth data with the inclusion of two vignettes due of the sensitive nature of the topic. Unstructured interviews would also allow the participants to use their own words and develop their own thoughts (Denscombe, 2006). However, both unstructured and semi-structured interviews seek discovery as a central aim, leading to in-depth investigations and exploration of personal accounts of experience and feelings (Denscombe, 2006).

Semi-structured interviews were chosen because the data was based on the nurses' experiences, emotions and feelings, rather than factual matters, and was aimed at discovering complex issues and personal accounts during the withdrawal process. My rationale for using the semi-structured interview approach with an interview guide was to allow the participants to talk freely; but at the same time, the nature of the topic could induce intense emotions so I realised that the participants may require gentle prompting as well. For this reason, I included the vignettes first, followed by the participant's own experience of withdrawing treatment. I was optimistic that the participants would develop and speak freely and widely on the issues raised by the vignettes, and this is what did occur during the interviews.

The interviews lasted approximately one hour and the interviews were conducted in a separate private room within the intensive care complex, but away from the busy

activities of the ICU. The research explored the sensitive aspect of dying and death which necessitated careful consideration with mutual trust and rapport between the researcher and the participants. Themes which emerged from the observation were incorporated into the interview guide, adopting Spradley's (1979) interview guide together with the two vignettes and the participant's own experience of withdrawing treatment. Vignettes were used to provide a less threatening way of explaining a sensitive topic and to enable the participants to define the situation in their own terms. Hill (1997) suggests vignettes are short scenarios in written form intended to elicit responses to typical scenarios. Each vignette consisted of a scenario which depicted a situation in the ICU that led to the decision to withdraw treatment from a critically ill patient. Both female and male genders were incorporated into the vignettes, as was a difference in age for the patient profiles in the vignettes. The vignette may be described as a flexible and fertile component of qualitative research which makes it a worthy consideration when researching nursing health-related topics (Richman and Mercer, 1991). Vignettes are short, descriptive literary sketches inspired by actual events, which use minimal resources, are easy to administer and mirror similar clinical situations (Richman and Mercer, 1991; Paddam, Barnes and Langdon, 2010).

I used vignettes to elicit knowledge relevant to the described situation in the ICU. Participants read the vignettes and responded to questions posed by me at the beginning of the interview. The vignettes I compiled were brief, understandable and had enough contextual information to allow the participants to understand the scenario. Typical cases comprising male and female genders, young and old level 3 patients from the intensive care environment were included in the two vignettes. The participants did not read the vignettes out loud. Paddam, Barnes and Langdon (2010) suggest the potential for bias is reduced by allowing the participants to read the

vignette quietly themselves, which ensures high internal validity and reduces researcher effects. The first vignette described an elderly patient and the second vignette described a younger patient. An example of the vignettes may be found in Appendix H.

Informed written consent was obtained from each participant prior to the interview and the interview process and their participation was explained. Participants' words were treated as a genuine reflection of their thoughts and experiences pertinent to the research topic, and the participants' voices were digitally voice-recorded to capture the interview data and were transcribed verbatim. The research interview relied on digital tape-recording backed up by written field notes (Denscombe, 2006). However, I used two recorders just in case one failed to record during the interview, and written field notes although these notes were scant. I maintained eye contact with each participant throughout the interviews. This interview talk was treated as 'on the record' and 'for the record', and was viewed seriously, together with an agenda for the discussion set by myself as the researcher. At the outset of the research interview, there was a degree of implied agreement that as the researcher I would control the proceedings and direction of the discussion; however, flexibility was employed with regard to the order in which topics were considered and discussed, allowing the participant to develop ideas and speak widely on the issues raised by myself. The participants were in agreement with this arrangement. The answers were open-ended with increased emphasis on the participant elaborating on points of interest. I conducted eight interviews, and selected participants with varying years of intensive care experience to obtain a reasonable representation of the intensive care nursing population within the unit, as it would have been impossible to interview the entire nursing population of 116 nurses. A pilot interview was conducted prior to the

fieldwork and the actual interviews, which offered insight into what I may expect as a novice researcher.

To minimise the impact of the researcher on the research interview, I adopted a neutral and passive stance, dressed in the usual attire of theatre scrubs worn by all staff within the intensive care unit, and wore an identification badge reflecting my name and position as a researcher. In order to optimise the interview, I was attentive and sensitive to the participants' feelings and periods of silence during the interview, and listened intently to what the participants said. However, I acknowledge that it was necessary on a few occasions to use prompts and probes during the interview. This was usually due to a certain degree of nervousness on the part of the particular participant.

During the interview, the ambience and aspects of non-verbal communication were captured in the tone of the participants' voices, laughter and, at times, quiet tears. During the interview process, if any participant had experienced discomfort or distress due the emotive nature of the topic, the interview would have been immediately terminated and the participant would be afforded debriefing and clinical supervision as a supportive measure. This fortunately was not necessary. I remember on one occasion a participant did become a little tearful but not distressed, and when I enquired if the interview should be terminated, the participant declined the offer. There was no need for debriefing any participant after the interview. I thought that the participants viewed the interview as giving voice to their experiences in a non-judgmental manner, and that in fact the interviews actually appeared to be cathartic for most of the participants.

5.3.5 Witnessed scenarios of withdrawing treatment

Critically ill patients present with a complex portrait of acute and chronic disease entities which necessitate advanced treatment interventions and technological supportive therapies. However, when this supportive treatment is no longer effective, treatment cessation is indicated. Once the decision to withdraw treatment has been confirmed by the doctor, the nurse caring for the patient sets the scene to manage the practice of withdrawing treatment from the patient. Further decision making becomes a nursing responsibility and the withdrawal process is a nurse-led practice in the UK. The family is invited to attend a meeting with the consultant and nurse in order to break the news and inform them regarding the decision to withdraw treatment. The patient is usually washed and made comfortable, and all unnecessary equipment is removed from the bed space with the curtains around the patient drawn to ensure dignity, respect and privacy for the ensuing event of withdrawal of treatment. The nurse and family will be positioned around the patient, who will be unconscious and motionless due to the sedative and analgesic therapies which will be maintained throughout the process. The closed curtains shield the patient, family and the nurse from the rest of the activities which continue in the ICU.

During the observation phase of the study, a series of scenarios where treatment was withdrawn in critically ill patients occurred. I subsequently witnessed six scenarios where life-sustaining treatment was withdrawn from critically ill patients in the ICU. However, I was not at the patient's bed space behind the closed curtains when the treatment was withdrawn; instead I positioned myself at the nurses' central station. The rationale behind this decision was as a sign of respect for the patient, family and nurse, and also because each patient's haemodynamic parameters which were visible on the bedside monitor were also visible on the central monitor screen at the nurses' station. As a critical care nurse I was able to observe the screen in front

of me, and interpret the data as I visualised the physiological parameters changing and the dying pattern unfolding on the monitor screen.

The patients' ages ranged between 30 to 72 years old. Following the withdrawal of treatment, the patients' dying trajectory until death lasted between 10 minutes and 7 hours. All six patients died in the ICU; no one was transferred to the ward, as additional intensive care beds were available for emergency admissions.

Journal entry: (31/08/11)

I recall a poignant moment after witnessing a case where treatment was withdrawn in a young patient with sustained multiple organ failure no longer responsive to maximum life-sustaining therapies. A man and a woman looking visibly upset quietly enter the patient's bed space behind the closed curtains. I then hear sobbing and barely audible voices talking in a low tone coming from the patient's bed space. The patient's decreasing numerical values on the nurses' station monitor appear to reflect the unfolding scene which is taking place behind the closed curtain. This is later confirmed by the nurse when I enquire about it. Suddenly the hissing noise stops, the crying is now audibly louder at the bedside for a short period of time and then there is silence. A few minutes later the woman supported on the arm by the man emerge from behind the curtains followed closely by the nurse and together they exit the ICU. The nurse returns to the ICU after about 15 minutes and notifies a doctor (later find out this is the anaesthetic registrar) of the patient's death. He then enters the patient's bed space and apparently certifies the patient's death. The man and woman do not return to the ICU.

The curtain is only opened again after the nurse and another nurse have conducted the last offices and the patient's body is removed to the hospital mortuary. The nurse takes a break for 30 minutes in the staff tea room. I notice the nurse preparing another bed area for a patient who has collapsed in a surgical ward.

5.4 Leaving the field

During the fieldwork, a sense of reciprocal trust and respect developed with the nurses I observed and interviewed. I also engaged in several conversations with doctors who were interested in my study. Spending 144 hours in the intensive care milieu with the nurses leaves one feeling a part of the people and the place, interwoven into their social structure of clinical practice and the routine of daily life in the ICU. In a strange indescribable way I shared their tears, fears, frustrations and

their world during my time in the field. At the time, disengagement from the field felt like an emotional severance from the people who had become a part of my life as a researcher through the study. The personnel became an integral part of my doctoral journey of discovery. In turn, I think I also left a part of myself in the ICU. My appreciation and respect for all these wonderful nurses remain immeasurable. Interestingly, when I returned to the ICU on my link lecturer visits after leaving the field, the only change I felt was within me: I was back to being an academic again, discussing and supporting students and mentors in the ICU clinical placement. I do not believe that there would be a downside keeping engaged with the personnel after completing the research. I remain the academic link lead for this area, and regularly conduct link visits to discuss student progress and mentorship updates.

Lofland and Lofland (1995, p. 63) offer the following advice regarding disengagement and leaving the field:

- *Inform people of your plans ahead of the time and try to avoid leaving abruptly.*
- *Explain why and where you are going.*
- *Say your goodbyes personally.*
- *Promise to keep in touch.*
- *Where appropriate, keep in touch.*

However, I realised that I would not completely leave the field when my fieldwork had ended because of my link lecturer role at the university where I work. This role has fortunately facilitated a continuity of the friendships that were formed during the fieldwork. On a regular basis I visit the ICU and have brief discussions with the nurses I met during the fieldwork phase. Whenever I visit the ICU nowadays, I am always greeted with a smile and questions regarding the completion of my doctorate.

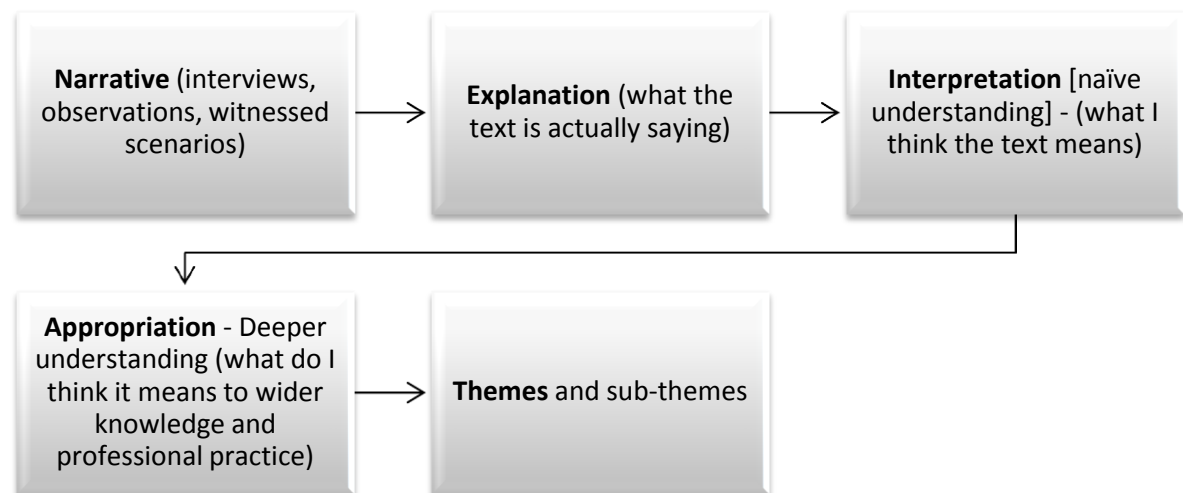
My personal coffee mug I used during the fieldwork and left behind is still visible on the shelf in the staff tea room, and is hopefully used often.

5.5 Data analysis

During the data analysis phase of this study, I experienced a sudden personal bereavement whereby a young member of my immediate family was admitted to an ICU in a critically ill state following a tragic accident which resulted in withdrawal of treatment. My bereavement necessitated delaying further analysis for a period of time as I felt too close to the data and the study. However, with time, I returned to the data analysis, perhaps with new insight. I realised that I would need to exercise sufficient control over my personal beliefs, attitudes and experiences as a nurse practitioner for the purposes of the production and analysis of the data. In order to achieve this aspect of the data analysis, I initially intended to use Spradley's (1979) domain analysis to provide a pathway for the analysis of meanings. However, I found Spradley's format appeared to be rather compartmentalised and not suited to my researcher style, which led me to venture further afield in my quest for a conducive analytical framework. I finally chose Paul Ricoeur's (1973) analytical framework to analyse my data. It may be argued that Ricoeur's (1973) framework is aligned to a phenomenological approach of data analysis and that I should have searched for a more ethnographic framework. However, I felt a connection with Ricoeur's framework as it kept me focused in setting aside my clinical practitioner experiences during the explanation and interpretation (naïve understanding) phases of data analysis. Yet within appropriation (deeper understanding), I was able to incorporate the self into the wider knowledge and clinical practice of the interpretation of the themes and sub-themes (Ricoeur, 1973). Additionally, Ricoeur's (1973) framework appeared logical and made sense of the data in the interviews, observation and field notes.

Data from the interviews analysed the nurses' narratives in terms of their views, as well as to what was happening in the two vignettes and the participants' own experiences of withdrawing treatment. Figure 2 is a diagrammatic representation of Ricoeur's (1973) analytical framework.

Figure 2: Diagram of Ricoeur's (1973) framework of analysis used for this study



Ricoeur's analytical framework first level is explanation which considers the internal value of the text and is seen as having no context, no author and no audience. What then arises from this explanation is based on a literal consideration of what the text is actually saying or what the text says (Dreyer and Penderson, 2008).

The second level involves the process of understanding what the text is 'talking about'. The analysis moves into the area of interpretation, and its outcome is what Ricoeur describes as naïve understanding of the text or what the researcher thinks the text means (Dreyer and Penderson, 2008).

The third level is an appropriation or making one's own in-depth understanding of what the text is talking about, which involves a process of the researcher moving back and forth between explanation (what the text says) and appropriation or deeper understanding (Dreyer and Penderson, 2008). The interpretation is informed by the

knowledge, experience and beliefs that the researcher self brings to the task, and what this means to wider knowledge and professional practice (Dreyer and Penderson, 2008). Explanation is the starting point where the researcher moves back and forth between explanation and interpretation. Naïve understanding or interpretation is a subjective, intuitive but superficial understanding of the whole, which then follows on to the next step of structural analysis and deeper understanding termed appropriation, which in turn gives rise to the themes and sub-themes of the study (Lyckhage & Lindhal, 2012).

According to Geanellos (1999), Ricoeur's theory of interpretation provides an approach whereby researchers can strive to achieve consistency between philosophy, methodology and method. My choice of Ricoeur's framework for data analysis for this study is based on his theory which acknowledges the interrelationship of interpretation and the researcher (as interpreter), and moves from naïve understanding where the interpreter has a superficial grasp of the whole of the text to a deeper understanding, thus affording the researcher the opportunity to develop intersubjective knowledge. Geanellos (1999) notes Ricoeur's theory includes distancing, appropriation, explanation and understanding. Ricoeur (1976) suggests interpretation is linked to language and experience, where experience is expressed through language and then transcribed into text and interpreted.

Czarniawska (2012) states that there is also the aspect that Ricoeur coined distancing which points out the difference between speech and writing as discourse – in other words, text has acquired a distance from speech. Czarniawska (2012) suggests meaning as text then has a longer life than just the event of speech. When a researcher analyses text as narrative, according to Czarniawska (2012) the researcher does not know who the audience is going to be – the unknown audience – but in the interview we do know who the audience is as it is the researcher and the

participant. Distanciation according to Ricoeur tries to objectify the text by freeing it from the author's (participant's) intentions (meanings) and giving it a life of its own (Czarniawska, 2012). A text never has only one meaning and there is not just one probable interpretation, but one interpretation can be more suitable than another and the argument gives credibility and validity to the interpretation (Ricoeur, 1981; Kemp, 1996). Therefore the researcher tries to understand the text by following the movement from what the text 'says' to what it 'speaks about' and 'what it means', which involves moving between explanation and interpretation. Ricoeur aimed to objectify the text, as he believed that by removing the authorial intent the idea that the meaning of the text resides only with the author (the research participant), objectification would allow researchers to move beyond the notion that only one understanding is meaningful or correct (Ricoeur, 1974, 1981). This would lead to textual plurality (where interpreters interpret the text differently) and multiplicity (texts have several meanings) [Geanellos, 1999]. However, in my study I have included the narrative voice as evidence in chapters 6, 7 and 8.

An experience-centred approach to semi-structured interviews assumes they may be sequential and meaningful, are human in nature, represent experience, reconstitute it as well as express it, and display transformation or change (Ricoeur, 1974, 1984; Andrews, Squires and Tamboukou, 2011). According to Squires (2011) experience-centred narratives are successive in time and represent meaningful accounts of personal experience that people produce, and are defined by theme rather than structure. In this study the interviews were sequential and meaningful narratives of the participants' personal experiences of withdrawing treatment.

In a way, these accounts may be event narrative, but may also be more flexible about time and personal experiences (Squires, 2011). Withdrawal of treatment is viewed as an experience-centred narrative in that it addresses a particular life event

(Denzin, 1989) or living through a traumatic event. The entire narrative is told to a researcher where dialogue embraces what the participant says, and where meaningfulness is located in the participant's words and the participant-researcher interaction. This participant-researcher interaction involves their respective life worlds which forms the constitutive characteristic of narrative (Squire, 2011). The personal narrative involves interviewing several people about a specific topic (Squire, 2011). Meaningfulness emerges because texts provide accounts of personal experience, by the use of the first person oral narration of past and present experience of withdrawing treatment in critically ill patients within the ICU (Squires, 2011).

Narratives are the means of human sense-making and the experience-centred approach assumes that temporal orderings of human experiences into narrative are not just characteristic of being human, but actually make us human (Squires, 2011). Time is human as it is articulated through a narrative mode and as Ricoeur (1984) suggests the examination of a life, without which life is not worth living, consists in the recounting of it (Squires. 2011). The psychologist Bruner (1990) goes on to say that humans have an inborn tendency to tell and understand narrative accounts which draw on the Aristotelian account of human mortality as developed and transmitted through the meaning-making activity of storytelling (Squire, 2011). Narrative accounts are not only human, but also social because storytelling constitutes and maintains sociality according to Denzin (1989).

In experience-centred narrative, the account involves some reconstruction across time and place. Narratives cannot be repeated exactly, as words never mean the same thing twice (this is why I did not give the transcribed scripts to the participants to read and confirm as correct) and narrative accounts are performed differently in different social contexts. Ricoeur (1984) suggests narratives are jointly told between writer and reader, speaker and hearer. The context of the research begins with the

research situation's interpersonal context, and includes the broader social and cultural contexts (Andrews *et al*, 2011). Narratives are also pertinent sources of truths of tradition according to Andrews *et al*. (2011). Experience-centred research assumes that narratives represent personal changes and are often interested in what constitutes a 'good' human story (Andrews *et al*, 2011). Narrative analysis therefore encompasses a range of techniques for interpreting the meaning of texts and structuring stories (Bentz & Shapiro, 1998). In this study, the analysis of narratives as data was used to access the world of the participants in an attempt to locate common themes among their experiences.

5.5.1 Emergent themes

The field notes collated from the observation and witnessed scenarios in the ICU helped to offer more depth to the study, while serving as a comparative reference to the data from the interviews. The inclusion of the verbatim quotes from the participants in the narrative is an attempt to capture the nurses' meaningful experiences of being in the culture at a given moment in time during a specific event. Reflecting on the interpretation of the participants' texts, I realised that a text never has only one meaning and there is not just one probable interpretation, but one interpretation can be more suitable than another and the argument gives credibility and validity to the interpretation (Ricoeur 1981). Withdrawing treatment in critically ill patients was thus a sequential event in time for the nurses in the ICU which shaped meaningful experiences in the participants' lives. Meaningful stories of personal experience that people produce are defined by theme rather than structure (Squires, 2011).

A number of themes and sub-themes emerged from the analysis and interpretation of the data collated during the study. I reviewed all the themes and

collated them into three key themes. Following this, I then characterised and named each of the three findings chapters (Chapter 5, 6 and 7) after a poignant theme that emerged from the narrative.

For the nurses, these themes unfolded as sequential experiences and events in a naturally occurring manner, commencing with the initial decision to withdraw treatment in the patient, the actual withdrawal process and the subsequent dying trajectory following withdrawal of treatment. All the participants during the study were given fictitious names.

Table 2 represents an overview of the themes and sub-themes from the observation, field notes, interviews and vignettes which emerged from the data.

Table 2: Overview of themes and sub-themes

Themes	Sources	Theme 1: Decision to withdraw treatment	Theme 2: Nurses' actions following the decision to withdraw treatment	Theme 3: Shared experiences in the journey towards death
Sub-themes	Observation	protecting/sheltering the patient; maintaining privacy; respect for dying patient; traffic light sanctioning; restricted and privileged entry and exit; private access only; creating a space for dying; spatiality; creating a space for dying and death; start of end-of-life care – planning; description of the ICU where the study was conducted; clinical environment and culture; place where dying occurs; people who work in the ICU.	deciding to withdraw; decision making process; medical decision making; nursing involvement in decision making; family involvement and agreement in decision making process; breaking the news regarding futility of further treatment; nurses' emotions and behaviour; nurse involvement during withdrawal of treatment; nursing care of patient; nurses' own sadness and grief; withdrawing treatment viewed as a failure; end-of-life care – planning and implementing; withdrawing treatment;	parallel journey to death; silent patient/nurse/family on parallel journey; end-of-life care; rites of passage/liminality; caring for the patient and simultaneously supporting the family during the patient's dying trajectory; end-of-life care – implementing; supporting the family; nurses' roles involve information broker, advocate and supporter for the family; 'being there' for family;

Themes	Sources	Theme 1: Decision to withdraw treatment	Theme 2: Nurses' actions following the decision to withdraw treatment	Theme 3: Shared experiences in the journey towards death
			<p>nurses' knowledge and experience in ICU;</p> <p>withdrawing treatment is a process conducted by nurses;</p> <p>palliative care at end of life;</p> <p>ensure pain free and comfortable patient;</p> <p>aim for a good death;</p> <p>end-of-life care – implementing.</p>	
Sub-themes	Field notes	<p>protecting/sheltering the patient;</p> <p>maintaining privacy;</p> <p>respect for dying patient;</p> <p>traffic light sanctioning;</p> <p>spatiality;</p> <p>creating a space for dying and death;</p> <p>start of end-of-life care – planning;</p> <p>clinical environment and culture;</p> <p>place where dying occurs;</p>	<p>deciding to withdraw;</p> <p>decision making process;</p> <p>medical decision making;</p> <p>nursing involvement in decision making;</p> <p>family involvement and agreement in decision making process;</p> <p>breaking the news regarding futility of further treatment;</p> <p>nurse involvement during withdrawal of treatment;</p> <p>nursing care of patient;</p>	<p>silent patient/nurse/family on parallel journey;</p> <p>caring for the patient and simultaneously supporting the family during the patient's dying trajectory;</p> <p>end-of-life care – implementing;</p> <p>supporting the family;</p> <p>'being there' for family.</p>

Themes	Sources	Theme 1: Decision to withdraw treatment	Theme 2: Nurses' actions following the decision to withdraw treatment	Theme 3: Shared experiences in the journey towards death
		<p>people who work in the ICU;</p> <p>description of the ICU where the study was conducted.</p>	<p>nurses' own sadness and grief;</p> <p>end-of-life care – planning and implementing;</p> <p>withdrawing treatment;</p> <p>nurses' knowledge and experience in ICU;</p> <p>withdrawing treatment is a process conducted by nurses;</p> <p>palliative care at end of life;</p> <p>visible dying (on computer screen at nurses' station), invisible dying (behind the closed curtains),</p>	
Sub-themes	Interviews	<p>protecting/sheltering the patient;</p> <p>maintaining privacy;</p> <p>respect for dying patient;</p> <p>spatiality;</p> <p>creating a space for dying and death;</p> <p>start of end-of-life care – planning;</p>	<p>deciding to withdraw;</p> <p>decision making process;</p> <p>medical decision making;</p> <p>nursing involvement in decision making;</p> <p>family involvement and agreement in decision making process;</p> <p>breaking the news regarding futility of</p>	<p>silent patient/nurse/family on parallel journey;</p> <p>end-of-life care;</p> <p>rites of passage/liminality;</p> <p>caring for the patient and simultaneously supporting the family during the patient's dying trajectory;</p>

Themes	Sources	Theme 1: Decision to withdraw treatment	Theme 2: Nurses' actions following the decision to withdraw treatment	Theme 3: Shared experiences in the journey towards death
		<p>clinical environment and culture;</p> <p>place where dying occurs;</p> <p>people who work in the ICU.</p>	<p>further treatment;</p> <p>nurses' emotions and behaviour;</p> <p>nurse involvement during withdrawal of treatment;</p> <p>nursing care of patient;</p> <p>nurses' own sadness and grief;</p> <p>withdrawing treatment viewed as a failure;</p> <p>end-of-life care – planning and implementing;</p> <p>withdrawing treatment;</p> <p>nurses' knowledge and experience in ICU;</p> <p>withdrawing treatment is a process conducted by nurses;</p> <p>palliative care at end of life.</p>	<p>end-of-life care – implementing;</p> <p>supporting the family;</p> <p>nurses' roles involve information broker, advocate and supporter for the family;</p> <p>'being there' for the family.</p>
Sub-themes	Vignettes	<p>nurses' previous experiences and knowledge of withdrawing treatment;</p> <p>nurses' knowledge of managing a</p>	<p>family support;</p> <p>caring for the dying patient;</p> <p>conducting the withdrawal of treatment;</p>	<p>family support;</p> <p>caring for the dying patient;</p> <p>family presence at patient's bed</p>

Themes	Sources	Theme 1: Decision to withdraw treatment	Theme 2: Nurses' actions following the decision to withdraw treatment	Theme 3: Shared experiences in the journey towards death
		<p>critically ill patients in the ICU setting – nurses as protagonists, especially nurses with experience in ICU;</p> <p>rationalising the decision to withdraw treatment;</p> <p>family agreement regarding the decision to withdraw treatment extremely important for nurses;</p> <p>planning the withdrawal process; breaking the news to family;</p> <p>supporting the family at this sensitive time important.</p>	<p>nurse-led practice;</p> <p>withdrawing treatment may be viewed as a failure;</p> <p>age of patient – difficult to withdraw from a young patient;</p> <p>important that family are fully informed of rationale regarding decision;</p> <p>nurses educate family regarding patient's impending dying trajectory and death;</p> <p>nurses' 'feel part of family' – feel sad, filled with grief;</p> <p>maintain patient's comfort and pain free throughout withdrawal process;</p> <p>if cure not possible then allow dignity in dying.</p>	<p>side important;</p> <p>explanations offered as treatment is withdrawn so family understand dying trajectory and try to make sense of it;</p> <p>nurses' 'feel part of family' – feel sad, filled with grief;</p> <p>if cure not possible then allow dignity in dying.</p>

5.5.2 Reflections on transcribing

Etherington (2004) suggests audiotaping and transcribing are rarely acknowledged in qualitative research reports. Researchers are encouraged to include this aspect as part of the research process so that there is less likelihood of misrepresenting the data (Etherington, 2004). In this study, the analysis of the interview data commenced when listening to the audiotaped material. Only by transcribing tapes personally can the researcher remain close enough to the speakers' meanings because, as Etherington (2004) explains, a researcher who does not undertake this part of the work loses the opportunity that transcribing offers. Furthermore, listening to the tapes and transcribing them personally affords the researcher the opportunity to pick up on nuances, hesitations, pauses, emphasis and other ways that people add meaning to their words (Etherington, 2004). In this study, I used two audiotapes simultaneously just in case one became dysfunctional. I chose to transcribe the data myself although it proved to be a rather time consuming task, but I do believe the outcome was more than worth the effort, especially as a novice researcher. Transcribing the data personally allowed me to listen and hear more of what I might have missed during the interviews and kept me more intimately connected to the data. From listening to the audiotapes I could recall the particular idiosyncrasies of the different participants such as humour, laughter, apprehension and even a few tears. However, using Dragon Naturally Speaking software (www.nuance.com) did make the task easier once the voice recognition software was established to adapt to my southern hemisphere accent.

I did not return the transcripts to the participants for member checking because I believe narratives represent reality or provide access to a window into a reality. In addition, when I asked the participants if they would like a copy of the transcribed scripts, they declined. Several mentioned they were more interested in reading the

whole study and asked if a copy would be available to the ICU. I reassured them that a report would be made available once the study reached completion.

5.6 Rigour and authenticity

It is not possible to judge qualitative research studies against the same criteria that are used for quantitative research, as the criteria defined by one perspective may not be appropriate for judging another perspective (Guba and Lincoln, 1985). Qualitative research focuses on the exploration of human behaviour and searches for an understanding of people's actions, whilst quantitative research focuses on causal relationships described in terms of observation statements, verifications and prediction (Ryan-Nicholls and Will, 2009). Quantitative research uses mathematical models, statistical tables and graphs to report the research results in impersonal, third-person style. By contrast, after analysis, data derived from qualitative enquiry is used to clarify an experience, improve understanding of a complex phenomenon. or to offer insight into a participant's thoughts, feelings or experiences (Ryan-Nicholls and Will, 2009).

Rolfe (2004) suggests establishing quality in qualitative research appears to be an ongoing argument within the research literature. Furthermore, all research studies must be open to critique and evaluation (Long and Johnson, 2000). As a doctoral student, I have acknowledged the need to demonstrate rigour in this study by analysing and describing the participant's narratives during the interviews and observation, but it would appear that one's decisions regarding rigour of a research study are ultimately a matter of personal judgment. However, as Ryan-Nicholls and Will (2009) point out, even though commonalities exist among all types of qualitative research, the use of one specific set of criteria to evaluate rigour is insufficient due to the wide range of diversity among methods. Reliability and validity have distinct

meanings which relate to the positivist paradigm; however, Long and Johnson (2000) question their use in qualitative research. Judging rigour in qualitative studies and establishing quality criteria or reaching a consensus for qualitative studies is debatable (Rolfe, 2004). As an ethnographer, I was also part of the data collection process whereby I sifted through, analysed and made sense of the data during the interviews as well as during the transcription phase. The participants' experiences were interpreted as unique, as truth is believed to be relative (Ryan-Nicholls and Will, 2009). Each interview proved to be a unique interaction and not replicable as such.

In qualitative research, rigour offers an opportunity to establish how trustworthy the research is, which is done by clarifying its credibility, transferability and confirmability (Hammersley, 2004; Rolfe, 2006). Validity and reliability are viewed differently in qualitative research as compared to quantitative research (Hammersley and Atkinson, 2007). Validity implies the existence of 'objective fact' which I would argue is at odds with the interpretivist paradigm. Qualitative research involves interpersonal relationships that have an impact on the research and thus render the validity of qualitative subjective research questionable. However, using triangulation or multiple methods and a variety of data sources contributes to methodological rigour according to Hammersley and Atkinson, (2007). Reliability is also positivist in its orientation whereas qualitative research is about interpretation which accepts that truth may be interpreted differently (Guba and Lincoln, 1985).

Hammersley and Atkinson (2007) argue that every form of data may be potentially biased but by employing a variety of different forms one may either eliminate or highlight this bias by convergence. Triangulation was employed in an attempt to achieve rigour in this study. In this study, the data collection sources included semi-structured interviews with vignettes, participant observation (with witnessed withdrawal of treatment scenarios) and field notes which provided comparisons

during the course of the study. In addition, this study was underpinned by researcher reflexivity, which explains the researcher's assumptions and acknowledges the relationship between researcher and participants; this is more likely to produce an accurate representation of this study's topic (Philpin, 2006). Throughout the data collection phase I became part of the intensive care culture through exposure to the nuances of the daily life of the nurses within it. I acknowledge that as an ethnographer my particular cultural location and my own personal values and beliefs have helped to shape the conduct of the study and the data interpretation.

Denzin and Lincoln (2005) suggest using multiple methods or triangulation adds rigour, breadth and depth to any study. Although collected at different intervals, the interviews, observation and field notes in this study provided a comparison of data relevant to the same topic. The aim of using triangulation was to use different data collection approaches to attain a complete understanding of the phenomenon, and to ensure the findings reflected the true views of the participants from the interviews and observation.

Credibility, transferability, confirmability and dependability are the alternative criteria for judging the quality of interpretivist research according to Guba and Lincoln (1985). Credibility or the truth of the ethnographic account is assessed in terms of the researcher's reflection on the research process and the participants' ability to recognise their experience in the research account (Ryan-Nicholls and Will, 2009). The credibility of this study refers to confidence in the truth of the findings, which have been checked by my doctoral supervisors after prolonged engagement in the study. Furthermore, in order to afford credibility to this study every effort has been made to offer clear and reliable descriptions and interpretations of the participants' views and experiences during the withdrawal of treatment process. Triangulation

facilitated conclusions to be based on what constituted the truth for the participants.

Long and Johnson (2000, p. 32) state:

...credibility is enhanced when triangulation data concur and areas where congruence occurs should be given priority.

Confirmability is the degree of neutrality or the extent to which the findings of a study are shaped by the respondents and not researcher bias, motivation, or interest. To increase plausibility or rigour of the ethnographic study, Pellatt (2003) advises the researcher to include a reflexive account in the written report. I ensured confirmability in my study by explaining the sequence of the study and methods used. I documented field notes and memoing, which were further discussed and analysed through an iterative process during my supervision meetings.

Dependability is the qualitative researcher's equivalent to the term reliability (Rolfe, 2004) and indicates the findings are consistent and accurate. The selection of participants and collection and analysis of data were carried out only by me.

Dependability is ensured for this study through the documentation process, which describes the context of the research in detail where the reader is exposed to the data, methods, decision making and the findings, together with the researcher's reflexive internal dialogue throughout the study. Dependability facilitates an audit trail where the reader is able to follow the path of the researcher throughout the research process and understand how the researcher arrived at their conclusions. Ensuring dependability guides other researchers who may wish to conduct similar research; although the study cannot be replicated, it may be repeated in similar situations with similar participants (Holloway and Wheeler, 2004).

According to Polit and Beck (2010) trustworthiness refers to the degree of confidence that qualitative researchers have in their data, assessed using the criteria of credibility, transferability, dependability, confirmability and authenticity.

Furthermore, trustworthiness implies methodological soundness and adequacy according to Holloway and Wheeler (2004). In this study I sought judgments of trustworthiness by developing credibility and confirmability within the study, and used methodological triangulation (interviews and observation), reflexivity and thick description. The findings were compatible with the perceptions of the participants studied in order to maintain credibility and produce meaningful and insightful research. I am confident that the nature and findings of the topic may be useful in similar situations and participants within clinical practice in ICUs. Holloway and Wheeler (2010) state that in order to achieve confirmability, the research should be judged by the way in which the findings and conclusions actually achieve the aim and objectives of the study, and are not merely the result of the researcher's prior assumptions and preconceptions. I did not use member checking for my study because I concur with Sandelowski's (1993) viewpoint that member checking may be problematic. The rationale for not using member checking for this study included the fact that participants may experience anxiety regarding their disclosed ideas about issues in clinical practice, and may not accept the transcript of their interview or field notes of observation as a true representation of their ideas and contribution.

Guba and Lincoln (1985) suggest that a study is authentic when the strategies used are appropriate for the true reporting of the participants' ideas and viewpoints, when the study is fair, and when it aids participants to understand their world and influence changes.

I believe this study will empower the participants and other critical care nurses in understanding their world. The originality of this study lies in the fact that it explores how nurses manage the patient's end-of-life care and dying trajectory following the decision to withdraw treatment. The findings suggest that a unique relationship and experience exists involving a patient, nurse and family in the shared journey to death.

5.7 Summary

This chapter has described the second part of the research endeavour which is doing the research. It encompassed the sample and sampling strategy, data collection and data analysis and introduced the emergent three themes, followed by considerations of rigour and authenticity. Chapters 6, 7 and 8 will discuss the findings of this study.

Chapter 6: The decision to withdraw treatment

6.1 Introduction

Chapters 6, 7 and 8 represent the findings from the study which will be discussed under the three central themes, namely: the decision to withdraw treatment (chapter 6); nurses' actions following the decision to withdraw treatment (chapter 7); and shared experiences in journey towards death (chapter 8).

Chapter 6 includes a discussion relevant to the intensive care scene as the centre stage where withdrawal of treatment, deciding to withdraw treatment from a critically ill patient, and drawing the curtains and creating a space for dying all occur.

Quotes from the observation and interviews will be represented in italics.

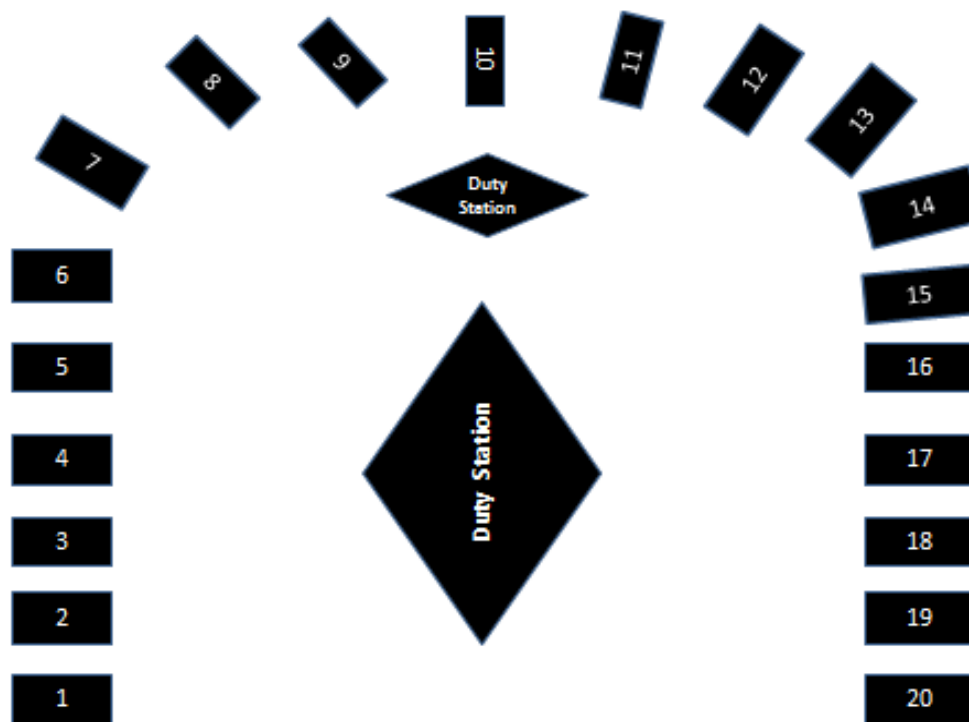
6.2 The intensive care scene

The ICU where the study was conducted comprised a large clinical space with an open landscape and a 20 bed capacity for treating critically ill adult patients of both genders. Consultant anaesthetists were responsible for the care of all the patients in the ICU and the majority of the qualified nurses had experience in critical care nursing. A senior pharmacist together with the intensive care medical and nursing staff formed the multi-disciplinary team. Decisions pertinent to each patient's treatment plan and therapeutic options were openly discussed and assessed in a methodical and pragmatic fashion, based on the available evidence and in the best interests of the patient on the daily ICU morning round.

Turnbill *et al.* (2005) described the intensive care unit as a clinical space which mirrors the notion of an intense world of hope, recovery and cure, as well as disappointment and loss. Every critically ill patient is afforded the opportunity to receive biotechnological life-sustaining therapies during their illness.

The entrance to the intensive care complex was well signposted and outsiders entered through large double doors. Before entering the next set of locked double doors, the area was flanked on the left by a large well-signposted and comfortable waiting room for the patients' relatives with a hot and cold drinks machine, toilet facilities and a bereavement/counselling room on the right. Access to the intensive care unit was restricted and only designated personnel with an appropriate swipe card were able to enter the unit. Philpin (2007) describes the ICU as a sequestered area separate from the rest of the hospital. For anyone else wanting to enter the ICU, access was monitored by a buzzer intercom and closed circuit television system at the two nurses' stations within the ICU.

Figure 3: Basic diagram of the structure of the ICU where the study was conducted



Upon entering the unit, a hand scrub unit was strategically placed on the right. This hand gel container was fixed to the wall for all visitors, relatives and other staff to use prior to entering the unit as a precautionary measure for infection control

purposes. The medical and nursing critical care personnel had access to the ICU complex through a separate, security-coded and locked entrance. This entrance was clearly marked 'staff only'. The ambience of the entrance to the ICU suggested that it was a secure area set apart from the rest of the hospital where a concealed community of practitioners clothed in blue uniform attire (also known as scrubs) delivered advanced healthcare to a specific patient profile. These medical and nursing practitioners reminded me of a hidden tribe in a world of their own. The patient profile is characterised by critical illness and a multitude of disease entities which require advanced technological support and specialised care. All critical care personnel, including the cleaning squad, were clothed in and identifiable by the blue scrubs, except for the consultant anaesthetists in charge of the ICU, who wore the blue top, but usually their own trousers. However, their names and staff status were only apparent on their identification badges attached to the pocket of the blue top covering their torso. The nursing and medical personnel appeared to be like a hidden tribe armed with an arsenal of expert knowledge, experience, compassionate care and innovative therapies in a quest to stabilise and rescue these critically ill patients from the 'brink of death'.

During my observation, on overhearing the personnel's conversations during the morning round, it was apparent that within this rescue culture of clinical practice, death appears to be viewed as an enemy and sometimes perceived as a disease rather than a way of life. The delivery of this specialised care within the rescue culture of the highly advanced technological therapies was embedded within a curative matrix. However, a focus of curative and palliative care appeared to co-exist within this milieu. Visiting medical and nursing personnel were not clothed in this blue attire, which signified their exclusion from the concealed community of practitioners. Physiotherapists were identifiable by their blue trousers and a white top with blue

braiding and radiographers wore blue pants with a maroon tunic. The pharmacist would wear ordinary clothes and usually carried a rather thick textbook which was apparently the equivalent to a pharmaceutical encyclopaedia.

The centre stage of the ICU consisted of the twenty designated bed areas each with an electronic, kinetic 'state of the art' bed and an adequate bed space with a collage of highly technological computerised monitors, mechanical ventilators, renal filtration machines, and a vast array of infusion pumps and syringe drivers. The actual ICU complex was surrounded by a maze of smaller rooms around the central zone which housed the twenty bed areas. The surrounding areas incorporated a large staff tea room, a conference room, toilet facilities, male and female change rooms, equipment storage rooms and several offices. The interior design of the unit was coloured by a floor of royal blue which flowed into sky blue and then crème, with large windows above each bed space allowing adequate natural light to filter through during daylight hours. This interior décor of the floor and supporting structures, which were also painted in royal blue, created an impression of the sea and sandy shore. In a symbolic sense, the area reminds one of the constant ebb and flow of the ocean, especially as the multitude of personnel conducted their daily work and activities around each patient's bed space and within the ICU complex itself. There was continuous movement in and out of the intensive care bed spaces and the surrounding areas of the ICU. This constant motion of people moving to and fro throughout the day and night symbolically appeared to reflect the waves of life, generating the eternal heartbeat of the intensive care milieu, pulsating with each patient's heartbeat – a continuous ebb and flow of life and often death. The beds were occupied by patients lying motionless, attached to various machines with lines, tubes and monitoring devices penetrating all areas of their bodies.

Whilst conducting my fieldwork, the nurse who conducted the aftercare clinic for intensive care survivors mentioned that several had verbalised this concept of the ocean and described the noises in the unit representing the constant flow of the waves. Royal blue sophisticated disposable curtains surrounded each bed space. Each curtain showed the date when assembled, date for renewal, the manufacturer's details and a hospital code for easy identification with regard to infection control initiatives. The ICU was air conditioned, and had an effective lighting system. This lighting system may be adjusted to mimic the circadian rhythms of day and night. The environment was a constant hive of activity, a purposeful flow of movement, staff talking, ventilators breathing, telephones ringing and different priority alarms triggering when a patient's parameters changed beyond the pre-set limits. This interior décor created a productive, yet rather serene and calm environment amidst the many medical emergencies that occurred on a daily basis. Whilst conducting my observation, it was not unusual to find a patient undergoing withdrawal of treatment and palliative comfort care in a particular bed space and in the opposite bed space, another patient receiving active resuscitation, all conducted behind closed curtains, yet clearly audible.

At the foot of each patient's bed space was a table with a very large intensive care chart. This chart allowed for documentation of the patient's parameters, blood results, various therapies, intake/output, infusions, intravenous medications, nutritional programme, treatment and assessment plan. The ICU chart serves as a legal document and evidence of the patient's life world and ICU journey for a 24 hour period. Various other A4 charts were also placed on the table, together with the patient's prescription chart. The patient's case notes were situated in a folder located in an attachment holder adjacent to the table. At each bed space, a patient diary was visible which outlined a summary of the patient's intensive care journey. The visiting

hours in the ICU were flexible: 13h30 to 16h30 and 18h00 to 20h00. Normally two visitors were allowed at each bed space; however, in the event of a deteriorating labile or dying patient, visiting routines were waived to allow the patient's family to be present at their bedside throughout the day and night.

The nursing staff's shift patterns were based on a day and night internal rotation system. Day shift schedules were from 07h45 to 20h15 and night shift schedules from 20h15 to 07h45. At each change of shift, a brief, fast track handover was delivered to all the nursing staff of the next shift in the staff tearoom by the charge nurse. The nurses were then allocated to their respective patients, and each nurse received a comprehensive individual handover for the patient she/he was caring for on the particular shift. This handover occurred at the patient's bed space. The function of the handover was to ensure the continuity of patient care by communicating pertinent information to the nurses on the oncoming shift. The nurse staffing ratio for level 3 patients was on a 1:1 basis. After handover, the nurse at each bed space routinely checked all equipment and intravenous infusions, administered prescribed medication and assessed the patient in readiness for the ensuing ICU round which usually commenced at 09h00. The practice development facilitator often accompanied and worked alongside a junior nurse. The charge nurse on each shift was supernumerary and acted in an advisory capacity overseeing all patient management and care throughout the unit. This charge nurse accompanied the anaesthetic consultant in charge of the unit for the day, together with the anaesthetic registrars and pharmacist, on the ICU round. The ICU round could take until midday to complete due to the complicated patient profile, number of patients and complexities of care. During the round, the nurse at each bed space presented the patient's assessment, progress, management and treatment plan for the day which was then discussed amongst the multi-disciplinary team. Turnbull *et al.* (2005)

suggest the doctors round, while a technical work routine determining the patient's management plan, may also be an ordering ritual where displays of power, deference and knowledge are apparent. On night duty, there was no formal ICU round, but the anaesthetic registrar on duty conducted an informal round at each patient's bed space and discussed the patient management and treatment plan for the night. The registrar was on duty all night and within easy reach in a room within the ICU complex.

Curtains were always closed around each bed space whenever a patient was assessed or care was administered as a token of privacy and respect. Once the decision to withdraw treatment in a patient had been agreed, the curtains were closed and usually remained closed. Throughout each shift, nurses were continuously monitoring and documenting the patient's vital parameters, checking ventilator and haemofiltration pressures, conducting bronchial toilet and suctioning, changing intravenous infusions, administering medications, and delivering holistic care to the patient's changing needs. The nurse's work in ICU appeared to be challenging even in calm periods, as the nurse was expected to make intelligent observations about the patient's condition, interpret subtle changes and judge the appropriate action to be taken. The nursing staff complement of the ICU comprised a total of 116 nursing staff (Bands 2, 5, 6 and 7), plus a Band 7 intensive care practice education facilitator and a Band 8 intensive care matron. Band 7 nurses fulfilled the role of charge nurses for the day and night shifts. The staff informed me that out of work socialising occurred in pockets of friends and that it took a while for them to get to know each other, which was understandable with such a large nursing complement.

I have used a system to identify nurses during the observation phase and field notes as nurse A and nurse B to differentiate from the fictitious names used for the participants in the interviews.

As one nurse explained:

It does make life interesting as you are usually working with different people on every shift, however when it comes to Christmas, we all try to get together for a party – with so many people it always turns out to be a very large party! (Nurse B)

When I commenced my observations in the ICU, some of the nursing and medical staff recognised me as the link lecturer from the university affiliated to the hospital. Initially some of the nurses and doctors thought I was doing a time and work survey on behalf of management, and were wary of my presence amongst them. However, with time, everyone accepted my researcher role, asked questions about why I had chosen the topic and eagerly shared their experiences with me. One of the domestic staff asked me if I was writing a story about the ICU. She informed me that she was very proud to be a member of the intensive care team and enquired if I would include what she had told me in my story.

The findings from the observations and interviews suggested that a critical care nurse was present at each level 3 patient's bedside 24 hours a day, continuously monitoring the patient's haemodynamic status, assessing, planning and implementing various treatment regimens. The critically ill patient was a passive recipient of care and treatment in the ICU, lying motionless and unconscious in the bed attached to an array of technological invasive life-sustaining devices. This induced motionless state was due to continuous intravenous infusions of sedation and analgesia, administered in an attempt to maintain patient comfort and a pain free state. Besides the patient, the nurse was also responsible for supporting the patient's family and keeping them informed of the patient's condition whilst conducting

continuity of care. This sense of closeness and ownership in reality signified both the nurse's focus of time and temporality, as well as the presence in a special 'space' or spatiality that was shared with the patient (Vouzavali *et al.*, 2011). The therapeutic use of self, temporality and spatiality were salient aspects within the clinical nursing remit of the intensive care nurses I observed. Cirlot (1995) suggests the patient becomes the place where the nurse's self develops and grows with experience. Nurses perceive the patient's body and bed space as a meeting ground which belongs to neither the patient nor the nurse, but rather to their relationship (Vouzavali *et al.*, 2011).

6.3 Deciding to withdraw treatment

The findings of the study indicate that the final decision to withdraw treatment was usually made on the morning ICU round between 09h00 to 12h00. The rationale for arriving at a decision to withdraw treatment from the patient in the morning was that it would facilitate adequate time to break the news to the family, plan and manage end-of-life care, and ensure that a strong contingent of personnel are available to care for the dying patient and support the family. I recall on a particular day in the field, overhearing the multi-disciplinary team discuss the withdrawal of treatment from a patient in the ICU. The nurse later informed me that withdrawing treatment in the critically ill patient was a complex decision, usually taken after consultation with members of the intensive care multi-disciplinary team, where a consensus was reached by the entire team involved in the patient's care management. The nurse informed me that nurses often initiated the discussion and guided doctors regarding withdrawing treatment, because they spent more time with the patient and family as compared to the doctors. This was highlighted by Jethro:

... as senior (experienced) nurses we have a close relationship with our consultants so we know it is their final decision but they usually consider our opinion and include us in the decision process ... (Jethro)

This integral involvement in the decision making process was echoed by the participants in the interviews, who described possessing the ability for critical thinking and assertiveness as key attributes towards their nursing role in the ICU, especially as experienced nurses. Experienced nurse involvement in the decision making process is well documented in the literature, where mention is made of how consultants respect the opinions of experienced nurses who often initiated a discussion regarding withdrawal of treatment (Coombs et al., 2010; Pattison, 2011). The issue of nurses' seniority and experience relevant to their involvement in the decision making process was highlighted by the following comments from two of the participants during the interviews:

...as a senior nurse in the ICU I have participated many times in withdrawing treatment especially from my previous experiences in a neurological ICU ... (Jethro)

I think the more senior you are and especially if you are in charge of the unit, then you often have to initiate the discussion regarding possible withdrawal of treatment with the doctors. (Uriah)

The final decision and responsibility for withdrawing treatment was vested in the consultant in charge of the ICU at the time. In my study, this responsibility was then transferred to the nurse caring for the particular patient who actually conducted the practice of withdrawing treatment from the patient. The current law within the United Kingdom obliges a competent and experienced physician to make the ultimate decision (ICS, 2009). During the study, the patient's diagnosis was the responsibility of the doctor (who was legally tasked with making the ultimate decision to withdraw treatment); however, the responsibility of managing the practice that constituted

withdrawing treatment resided with the nurse at the patient's bedside (Coombs et al., 2010). Withdrawing treatment from critically ill patients was thus a nurse-led practice in the ICU where my study was conducted. Several participants clearly expressed this viewpoint in the interviews, with the following two comments being most notable:

In my experience the consultant makes the final decision but as a team we discuss it and consider the patient and families' wishes prior to the illness...but I am the one who withdraws the treatment. (Abbi)

...the consultant made the decision to withdraw treatment after discussing this with the nursing staff and family ...and then it was up to me to withdraw the haemofiltration and inotropes etc. (Dylan)

During the observation phase, I observed a scenario where the decision to withdraw treatment was delayed when the family requested another 24 hours of intensive care therapy. After 24 hours, there was no improvement in the patient's response to maximum therapies. The patient was subsequently reassessed the following day and the decision to withdraw treatment was confirmed. The patient's management during the withdrawal practice appeared to continue in a compassionate and caring fashion. A nurse informed me that sedation and analgesia are maintained to ensure patient comfort and relieve pain, but not at dosages that may intentionally hasten death.

Re-assessing the patient and respecting the patient and family's wishes for a delay in the final decision making process was clearly expressed by a participant who said:

...sometimes the family requests another 24 hours of treatment because the patient would want this so the team should respect their wishes in this type of scenario ...and on the other hand often the family are happy to go along with the decision because the patient would want it that way. (Efa)

The interviews suggest that this delay in making the decision to withdraw treatment was often due to the family needing more time to come to terms with the decision or further explanation regarding the rationale for the withdrawal decision.

Glaser and Strauss (1965) recognised that dying was a social process and occurred over time. The time from withdrawing treatment until death was unpredictable. This was evident during my observation phase in the field. The findings from six witnessed withdrawal of treatment scenarios during my fieldwork revealed the time interval from onset of withdrawing treatment until death was between 10 minutes and 5 hours. This narrowed the time for nurses to plan the patient's end-of-life care and shape the dying journey for these critically ill patients.

The sedated unconscious patient's unawareness of their own death may be interpreted as 'closed' awareness, whereas the concept of 'open' awareness of dying was evident in the discussion between the patient's family, doctor and nurse regarding withdrawing treatment. Because the unconscious patient was not aware of their own dying due to their induced sedative and analgesic state during the withdrawal process, the death was hidden from the patient. Reflecting on Glaser and Strauss's (1965) concepts of 'awareness contexts', withdrawing treatment in the ICU may be perceived as a 'quick death'. However, this does depend on each individual case, but generally death soon followed when life-sustaining therapies were withdrawn.

I observed nurses maintaining professional composure by managing their emotional involvement with the patient according to their expectations regarding the patient's death. However, I did notice a nurse trying to hide her tears on a particular shift, and noticed a mood and behaviour change in another nurse when the decision was made to withdraw treatment. This nurse became noticeably quiet and subdued. Critical care nurses are trained to regard saving a patient's life as one of the highest

achievements in nursing (Glaser and Strauss, 1965). The intensity of intensive care work helps to take a nurse's mind off the patient's fate, thus reducing the nurse's conscious involvement and maintaining composure during this fraught and fragile time of withdrawing treatment (Goopy, 2006). I would add that from my observations, the closed curtains served as a mechanism to hide the nurse's emotional involvement to the dying patient and the family. It served a protective function, creating a safe haven for all behind the curtain. Additionally, nurses also relied on each other for mutual support to maintain their composure and to be reassured that everything conceivable had been done for the patient. This aspect was summed up by the following two participants' comments:

...as I was withdrawing the therapies, I felt the tears welling up but I knew I had to stay in control of the situation and not cry as this would upset the family even more ...they were a lovely family. (Ardelle)

...but as long as we have done everything for the patient and in their best interest, this is important in the decision making process. (Uriah)

Another two experienced nurses described the importance of peer support by stating that:

...we nurses support each other as much as possible during the withdrawal of treatment ...sometimes it is just being there that matters or being nearby ...(um) we all need support during this time... (Skye)

...the mortality rate is high in ICU, so we do expect death and not all patients in ICU are going to survive ...this is all part of the job. (Jethro)

One participant felt strongly about continuing treatment when the patient's prognosis appeared futile:

...you know from previous experience that to continue treatment is merely prolonging the inevitable, if the patient does not respond to maximum therapies, there is very little more we can do or offer – there is a time to withdraw. (Ardelle)

Coombs *et al.* (2010) suggest that futility occurs in healthcare when the therapy appears ineffective and serves no further purpose. Critical care nurses face a dichotomy situation where they intellectually rationalise the decision to forgo treatment in the critically ill patient as a palliative measure to prevent further burden from unwarranted treatment. It appeared difficult for the nurses to relinquish control over a situation where the [patient was saved from a probable death, rescued and supported by various therapies, only to have the treatment withdrawn again. Withdrawal of treatment appeared to induce a sense of failure in the following two participants:

... it is hard to let go when you have worked so hard saving the patient and then to just let them slip away ...I see it as a defeat ...but appreciate if we are unable to save a patient, then we need to give the patient a dignified death ...but it is difficult in the ICU ...because we save patients ...well most of the time (Abbi)

I think some staff see it as a failure ...they see it as a failure as they are there to heal and cure ...and to help. Personally I don't, but some do ...doctors and nurses. (Skye)

Accepting the futility of continued treatment in critically ill patients appeared to induce a sense of failure in nurses especially when patients had deteriorated to the point of dying, and their critical illness had not been resolved or reversed. Pattison (2011) explained this issue of failure by saying that this can often permeate feelings of guilt, frustration and anxiety about the decision making process. I would argue that the findings from my study's interviews and observation suggest that the nurses view withdrawing treatment more as failure than guilt. The nurses informed me that although everything conceivable had been done for a patient, when further treatment was ineffective, then the time was right to consider withdrawal of treatment. The nurses did, however, mention that after working so hard to save a patient from dying,

to acknowledge defeat did feel sometimes like a failure. This sense of failure was evident in the comments made by two nurses during my fieldwork:

...we have been fighting a losing battle for a few days nowThere is nothing more we can do ...It is such a pity ...feels like we have failed the patient. Although we have prepared the patient's family for this moment for the past 48 hours, it is still hard for them to accept. (Nurse E)

well, we did everything in our power to sustain the patient's life ...but unfortunately it was not good enough! (Nurse G)

Singer and Bowman (2009) suggest disease is viewed as being under the control of science and death is perceived as a failure of medical care. However, it is evident that in a curative focus of care, dying and death could be perceived as a disease which needs to be treated and cured. The nurses' challenge regarding this aspect of care spanned the focus of both curative and palliative care, with Seymour (2001) affirming the fact that death is often perceived as a 'failure'. This was evidenced in a comment made by a nurse during the observation phase:

I think to be fair, critical care doctors and some nurses see withdrawing treatment as a failure ...it was just very emotional and she was so young ...sometimes I think it feels like a failure when we withdraw treatment in a patient that we have tried to save and cure. (Uriah)

Fisher (2001) explained that the success of intensive care was not to be measured only by survival statistics, as though each death was a medical failure; instead it should be measured by the quality of lives preserved or restored, the quality of those dying and the quality of relationships involved in each death. Despite the best intentions of intensive care staff to provide more humane and compassionate end-of-life care, the prospect of dying and death, along with the silence that punctuates a family discussion about death and the feeling of desolation and hopelessness that death evokes, still induces a degree of physical and emotional

discomfort (Levy, 2001). In the ICU where the study was conducted, the meaning of death invoked feelings and notions of human failure especially in a curative focus of care. However, participants agreed that where cure was not possible, adopting a palliative care approach would provide comfort and dignity in dying in the ICU, which could be viewed as a good death.

McMillen's (2007) findings indicated that senior nurses' opinions and experience were valued by consultants and registrars alike regarding withdrawal of treatment and the decision making process. Jethro, a senior nurse in the ICU, summed up the nurse involvement in the decision making process:

I think a few of the more junior nurses may take it as gospel from the consultant and are led by them (the doctors) ...whereas I would be instigating the withdrawal of treatment option, questioning the rationale and generally being included in the discussion ...because as senior nurses we have the experience of this practice and we act on our patient's behalf. (Jethro)

Nurse practitioners have the capacity to challenge, the honesty to ask why, the empathy to care, the skill to perform competently and the determination not to be put down (Poncet *et al.*, 2007). The authors go on to explain that perhaps one reason why critical care nurses might be hesitant to engage in decision making is because it can be an incredibly stressful event and can increase the nurses' risk of burnout. In my study, it was evident that even though inexperienced nurses were included in the decision making process, their critical thinking skills and ability to question therapies were important to their participation in the withdrawal of treatment discussion.

Stayt (2009) explained the notion of the emotional costs of labour, regulated by the social exchange and human interactions which were involved in family care during end-of-life, and how these induced stress in nurses. Emotional labour in nursing involves the interaction between the person as a nurse and the person as an individual, and the belief that emotional engagement is a necessary attribute of

caring in an excellent nurse (Henderson, 2001). I would agree with Mealer *et al.* (2007) and Pattison (2011) who suggest that critical care nurses are at greater risk of suffering post-traumatic stress syndrome due to several influences. These include a combination of one-to-one ratio nursing; an advanced technological and high-pressure working environment; and the repeated exposure to stressful events (Mealer *et al.*, 2007; Pattison, 2011). Senior nurses often take the lead to initiate the decision making process regarding withdrawing treatment. In Bucknall's (2000) observational study of 18 nurses in both urban and rural critical care settings in Australia, the findings revealed nurses' years of experience and seniority status influenced their input to the decision making process. The nurses were assertive and questioned consultants during the decision making process regarding treatment withdrawal. However, nurses' involvement in the decision making process may be a stressful event, especially if the nurse is relatively new to the intensive care environment (Poncet *et al.*, 2007).

Nurses ultimately balance the primary needs of the dying patient in conjunction with supporting the family as they manage withdrawing treatment. The following comments from Efa and Jethro echo the nurses' involvement in caring for the dying patient and simultaneously supporting a family:

the nurse not only has to withdraw treatment in the patient but also support the family through the dying process, which is challenging as we only have one chance to get it right – you know to ensure a pain free and peaceful death for the patient and to be there and support the family so they are not alone. (Jethro)

...the patient's family were with her and held her hand and in turn I supported them all during her dying as we withdrew all inotropic support. (Efa)

6.4 Drawing the curtains and creating a space for dying

The findings of this study indicate that during withdrawal of treatment, the nurses viewed the patient's bed space as a protected place where the closed curtains sheltered the patient, nurse and family from the rest of the intensive care unit, other patients, personnel and clinical activities. The patient's dying and death unfolded behind closed curtains around the patient's specific bed space. Curtains surrounded each patient's bed space and when closed serve as a protective, restricted entry and an exit point. Behind each patient's bed was a visible number placed on the wall which denoted the particular bed space area for that particular patient. The ICU where the study was conducted had the capacity for 20 bed spaces.

During my observation, I was acutely aware that the patient's bed space represented the place where caring occurred and harboured a patient, nurse and family, yet restricted others. It represented the patient's living world within the larger ICU space. Vouzavali *et al.* (2011) and Cypress (2011) suggested a reciprocal and emotional relationship between the nurse, patient and family was fostered around the bed space throughout the patient's intensive care journey. In the ICU where the study was conducted there was ample bed space capacity for the surrounding technological and human resources. From a caring perspective, the patient's bed space represented an outer, spatial dimension and an inner existential dimension (Olausson, Ekebergh and Osterberg, 2014).

Prior to entry into a bed space when the curtains were closed, I noticed permission was obtained first, almost as an unspoken rule. All personnel observed this rule. Ardelle clearly stated:

...the patient's bed space is privacy for the family ...privileged entry really and dignity. The last thing the other patients' families want to see is a family in tears and a dying patient. (Ardelle)

On several occasions during my field work I overheard other nurses and doctors ask the nurse behind the closed curtain if they may enter by politely saying 'May I

come in?' It appeared to be a normal gesture among the intensive care personnel. The symbolic nature of the curtains was also apparent in Efa and Ziggy's comments during the interviews:

This is done as the family arrive ...to maintain respect and dignity for the patient and family, to screen them from the rest of the staff and traffic in the ICU ...and also to protect the other patients and their families. (Efa)

I think it provides a person more privacy ...and more importantly a space ...for the relatives ...as long as it shields the patient from other patients ...it provides a personal space for the nurse, relatives and the patientand it either invites you into this space or not ...you ask if you can enter ...yeah, the curtains are for personal space and privacy especially during dying. (Ziggy)

I observed the frequency of how often the curtains were closed, opened, semi-closed, opened and closed again in a 12 hour shift. In addition it was apparent that curtains were closed around the patient's bed space on different occasions, which included activities such as caring for or assessing a patient, implementing therapies, conducting procedures, during the intensive care doctors' round, and after the decision was made to withdraw treatment. I could hear the nurses talk to the patients as if they were awake and able to respond, but I noticed that when the curtains were opened again, the patient lay motionless as if in a deep sleep. If the curtains were opened for a prolonged length of time it was obvious that the particular bed space in the ICU was empty. This issue of the open and closed curtains was subsequently included as a question in the compilation of the vignettes for the interviews which were conducted after the observation phase of this study.

Bryan (2007) suggested that death was hidden in the acute hospital setting by curtains, and according to Costello (2006) the phenomenon of death in hospital was cloaked in secrecy. Bryan argued that apart from the ritual of closing curtains and nurses' reluctance to disclose information about death, there was little evidence to

support Costello's observation. I concur with Costello that curtains symbolise secrecy and perhaps fear of death. I believe that, in my study, the findings suggest the participants viewed the closed curtains as a token of respect and protection for the patient and family, where nurses attempted to create a private, conducive environment for dignified dying and death to occur in a busy ICU. The closed curtains almost symbolically shielded the feelings and emotions of the people behind them. This was evidenced from the interviews whereby the participants felt that the closed curtains screened the emotions of the nurse and family at the patient's bed space, thus creating a sense of emotional isolation from the rest of the ICU. The concept of closed curtains also served a function to protect everyone else in the ICU from having to witness the patient's dying and death.

Regarding the concept of spatiality, it was interesting to note that on a particular day during observation, the nurse who I was observing informed me how much it irritated her when the doctors' 'messed up' *her* patient's bed space or scribbled illegibly on *her* ICU chart. She went on to describe how meticulous and tidy she was, and that she was proud of this fact as the patient was her responsibility, and this included everything that was relevant to or belonged to the patient. This was her space and her patient.

When the participants in my study discussed the patient's bed space, it appeared to be a multidimensional concept which provided a place for nurturing, sheltering and dignified respect. The findings from Vouzavali *et al.*'s (2011) study identified the spatial aspects of the relationship between the patient and the nurse within the bed space. During the fieldwork, I observed how much time nurses spent at each patient's bed space engaged in what appeared to be an intense experience of caring, ownership and personal encounters throughout the patient's care. These experiences of caring appeared to influence the nurses' self-perception, and personal

and professional identity, and profoundly affect the way the nurses interpreted their world. It was thus obvious that symbolically an intimate bond existed between the nurse and (albeit unconscious) patient as a unity where the nurse and patient occupied the same space in a given moment in time. The nurses' spoke to their patients as if they could respond to them in a conscious state. Olausson *et al.* (2014) suggest a trusting relationship is established in the bed space as nurses try to create a homely environment and a conducive surrounding for a critically ill patient. For example, lowering the alarm sound level prior to activities that normally trigger them and arranging technologies around the bed in such a way as to allow the patient to remain the focus of attention (Olaussen *et al.*, 2014). Flowers were not allowed in the ICU, but a few patient family photographs, cards and iplayers were noticeable at patient bed spaces. The nurses I observed all seemed to take great pride in the responsibility invested in them for caring for the critically ill patient allocated to them during a particular shift. I never observed any nurses who were not intent on caring for these critically ill patients whilst in the field.

Abbi aptly described her interpretation of this bed space in her comment:

I told the family that I would be responsible for caring for their Mum for the next 12 hours 'cause she was my special patient and my priority for the next 12 hours and this was our space. (Abbi)

6.5 Summary

This chapter dealt with three emergent sub-themes. I described the intensive care scene as the centre stage where the decision making process to withdraw treatment occurs followed by the closing of curtains around a critically ill patient's bed space.

I set the scene by describing the intensive care milieu where the study was conducted. The intensive care environment was fashioned to sustain life with technological innovation and advanced caring, creating a milieu of life and death within a defined space.

This was the place where the critically ill patient's journey commenced. Every patient was afforded the opportunity to receive biotechnological life-sustaining therapies during their critical illness. Access to this area of the hospital was restricted, as was the area around each patient's bed space. Curtains enclosed each patient's bed space and served to offer protection, privacy and dignity for all when closed. The ICU was a hive of activity with a constant motion of people moving to and fro throughout the day and night, symbolically keeping the eternal heartbeat of the intensive care milieu alive. Sedated patients lay motionless on the beds with bodies penetrated by invasive tubes and lines connected to advanced technological monitoring devices. When maximum life-sustaining therapies no longer offered cure, then the decision making process was instituted, which involved discussion among the multi-disciplinary intensive care team. The consultant made the final decision to withdraw treatment, which was passed on to the nurse caring for the particular patient; further decision making was entrusted to the nurse as this was a nurse-led practice. The participants in this study perceived the patient's bed space as a place where a world of caring, supporting, life and death existed within the reality of the larger confines of the ICU space. This was a space and time where the patient's dying trajectory and death would unfold behind the protection of closed curtains with a nurse and the patient's family in attendance.

Chapter 7 presents the second central theme, namely nurses' actions following the withdrawal of treatment decision.

Chapter 7: Nurses' actions following the withdrawal of treatment decision

7.1 Introduction

This chapter discusses the second central theme of nurses' actions following the withdrawal of treatment decision. The sub-themes of nurses' emotions and behaviour and withdrawing treatment are included in the discussion.

7.2 Nurses' emotions and behaviour

The study findings indicate that nurses enacted different roles when caring for the critically ill patient during withdrawal of treatment and at end-of-life. Previous experience of withdrawing treatment, together with advanced nursing knowledge and patient-centred caring, emerged as important characteristics relevant to nurse involvement during end-of-life care. McMillen's (2007) grounded theory study conducted in the UK explored nurses' perceptions and feelings regarding end-of-life decisions in an ICU. Nursing experience was important as nurses with more experience of dealing with end-of-life decisions felt more comfortable with the decision to withdraw treatment (McMillen, 2007). In addition, the findings also indicated that consultants were more likely to recognise the experienced nurses' length of experience within the ICU, and were prepared to consider the nurses' views and opinions regarding the decision to forego treatment (McMillen, 2007). Experienced nurses in my study displayed a proactive and assertive attitude with regards to their contribution towards the decision making process. This was apparent in the interviews when Efa suggested:

...the patient has come to the end of the road as far as intensive care therapies are concerned ...there is very little more we can do now and it would be futile to continue. (Efa)

Furthermore, nurses' roles within intensive care settings have evolved during the past few years since the inception of several nurse-led practices in the UK; for

instance, withdrawing treatment from critically ill patients (Coombs *et al.*, 2010; Latour *et al.*, 2009). Experience and confidence in critical care nursing embrace the key characteristics of the nurse which was apparent in the following comment from Uriah:

During withdrawal of treatment experience and confidence comes into it ...to be a good communicator and be confident with people and to be able to speak to people at their level ...to be confident in evaluating a situation and dealing with it appropriately ...especially with end-of-life.
(Uriah)

McLeod (2014) emphasises the issue of good communication as key to both making the decision to withdraw and the actual process of withdrawing treatment.

Level 3 critically ill patients are nursed on a 1:1 ratio during the patient's intensive care journey. Assessing and implementing quality care according to the patient's holistic needs necessitates constant attention, a sense of closeness and belonging for the nurses who remain at the patient's bedside throughout the day and night. A nurse accepts responsibility and accountability for the care of their allocated patient, and symbolically the patient becomes 'a part' of the nurses lived world whilst on duty in the ICU. A poignant closeness exists between the nurse and a critically ill patient as both the patient and the patient's bed space thus befit the domain of the nurse. Cirlot (1995) suggested the patient becomes the place where the nurse's 'self' develops and grows with experience. According to a phenomenological study conducted by Vouzavali *et al.* (2011) involving 12 intensive care nurses, the nurses perceived the patient's bodies and bed space as a meeting ground which belonged neither to the patient or the nurse but rather to their unique relationship. This close connection between a critical care nurse and patient was mediated by the immediacy of the body. Vouzavali *et al.* (2011) proposed that nurses perceived the handling of the patient's body and fluids at a deep level, as an approach to a patient's soul, thus extending the connection beyond the body, which encompasses psychological and

spiritual dimensions. The nurses I observed all appeared to experience intense, intimate relationships with their patients and often with the patient's family. I discussed the nurse/patient/family relationship with some of the nurses during my observation, and it was evident that this unique relationship was meaningful and elicited powerful feelings throughout the patient's subsequent intensive care journey (Vouzavali *et al.*, 2011). Dylan's comment highlights this concept:

...if you think of the time and effort invested in saving the patient and the continuity of care with the patient especially if you are doing a string of shifts and looking after the same patient, you get very close to the patient ...and to their family. (Dylan)

Critically ill patients are central to nurses' meaning-making process and role perception, and the use of the 'therapeutic self' is a mechanism whereby critical care nurses communicate with sedated ventilated patients (Scholes, 1996). Caring for critically ill patients triggers emotions of compassion and concern in the nurse which form the basis for the development of the nurse/patient relationship in the ICU (Vouzavali *et al.*, 2011). Suffering and anxiety are everyday companions of nurses, and the process of empathising with patients during intense suffering often leaves hurtful imprints on the nurses (Vouzavali *et al.*, 2011). In my study this was especially true because the participants acknowledged their need to face their own fears of death before they could support patients and families to deal with death. The nurses were present at the patient's bedside 24 hours a day, embracing the patient with intelligent observation, holistic patient assessment, and planning and implementation of the various treatment regimens. Other nursing roles included supporting the patient's family and keeping them informed of the patient's condition whilst conducting continuous caring. This sense of closeness and ownership in reality denoted the nurses' focus of time and temporality, as well as the presence in a special 'space' or spatiality shared with the patient which was also evident in the

study conducted by Vouzavali *et al.* (2011). The therapeutic use of self, temporality and spatiality were salient aspects within the clinical nursing role during the observation phase. Nurses in the ICU cared for patients holistically, as individuals, each with their own needs. The patient was not perceived as a medical case, but as a person with a life filled with meaning. Nurses became involved with the patients emotionally and almost a part of their world. This emotional involvement makes it possible for the nurse to respond to the family in a sensitive and meaningful way (Seymour, 2001).

Nurses experienced deep emotional sadness during the practice of withdrawing treatment from patients and verbalised this sadness during the interviews. During the interviews, two participants described their deep sense of sadness when they withdrew treatment from patients:

...I felt a deep sense of sadness for the patient and his family as I withdrew treatment ...it is a sadness deep within me ...difficult to describe. (Jethro)

...it is always sad for the patient and the family and we nurses also experience their sadness ...their sadness becomes our sadness. (Efa)

Calvin, Kite-Powell and Hickey's (2007) American qualitative study found nurses expressed stress and difficulty in the transition from cure to comfort care, and the patient's situation induced emotions of sadness in the nurses caring for them.

Space is multidimensional according to Vouzavali *et al.* (2011) who state space is multidimensional and provides both housing and refuge. In clinical practice, time spent with a critically ill patient is awash with forceful experience, implicit encounters and strong feelings impenetrable to others. Symbolically, an intimate bond exists between the nurse and patient as a unity where the nurse and patient occupy the same space in a certain time. Ardelle and Dylan described this space and time aptly:

the time I spend caring for a patient and supporting their family is always very special ...this is our time and space. (Ardelle)

I enjoy always caring for intensive care patients because it is you and your patient in your own space ...and everything happens in this space at different moments in time during the patient's illness. (Dylan)

Zerubavel (1979) described the concept of temporality in the modern hospital as a complex social system. There was a marked difference in patient coverage between the doctors and nurses in the ICU. The doctors spent their time among all the patients in the ICU and a minimal amount of time at each patient's bedside, either conducting a procedure or reviewing the patient's progression on the ICU charts. In contrast, each nurse cared for their allocated patient continuously, occasionally leaving the bed area to replace different infusions, check blood gases or help another nurse with patient care. Time was a major parameter of social order in the ICU with social life structured and regulated in accordance with it (Zerubavel, 1979). This was evident in the handover procedure, administration of medications and daily routine tasks. The nurses never left a level 3 patient alone for very long, there was always another nurse overseeing the patient.

The concept of temporality was illustrated by the following comment from Ardelle during the interview:

the nurses are in a better position as compared to the doctors to withdraw treatment because we are caring for the patient 24/7 ...doctors just pop in and pop out ...we have established a rapport with the family and keep them informed of the patient's condition continually ...we get the full picture of the situation. (Ardelle)

Health and illness are therefore symbolically located in the sacred domain of almost every culture, and the temporal order which exists in hospital life is oriented toward patient coverage (Zerubavel, 1979). A patient's critical illness creates a

timeline of activities and events which forms a temporal and spatial trajectory (Reddy, Dourish & Pratt, 2006).

Spatiality and temporality within the context of hospital life were also evident in the patient's critical illness journey, intensive care encounter and during the dying trajectory following the decision to withdraw treatment. As the nurse managed the withdrawal of treatment from the patient, the temporal and spatial aspect of the dying trajectory unfolded around the confines of the patient's bed space, where death was a certainty but the time to death remained uncertain.

During my fieldwork I observed how the nurses acted as informative channels of communication between the family, fellow nurses and doctors. The nurses continually kept the multi-disciplinary team updated on the patient's haemodynamic status by assimilating and collating different types of information about the patient, which in turn informed their practice. I also noted on several occasions how the nurses educated the family regarding the patient's critical illness and explained the technology surrounding the patient's bed space whilst vigilantly observing the patient. The nurses told me that the families were aware that the different monitors and machines were sustaining the patient's life, which was often in a precarious balance. The nurses' role was to acclimatise the family to this fraught situation and emotional rollercoaster journey of waiting and hope during the patient's critical illness. As outsiders to the intensive care milieu the family's perception of the advanced technology and surrounding environment would naturally induce a degree of fear and bombardment with the unknown, especially with regard to the unfamiliar sights, sounds, smells and penetrated patient bodies. Patients' bodies were invaded by a multitude of invasive technological monitoring devices attached to programmed machines, which reflected multi-coloured numerical data and different flashing alarm systems on computerised visual screens. Whenever a machine alarmed, I noticed

that the family member would stare intently at the source of the alarm, probably fearing the worst case scenario as the very life and death of the patient seemed to be embodied within this invasive technology. By familiarising the family with regards to the vast array of technological bodily intrusion, the nurses tried to minimise the family's anxiety, yet simultaneously increase their understanding of the ICU culture. Adequate amounts of sedation and analgesia were maintained routinely to ensure comfort and a pain free state in the silent unconscious patient.

Additionally, the nurses appeared to be mediators between the doctors and the family and often acted as advocates on behalf of the family and indirectly on behalf of the unconscious, critically ill patient. Once the decision was made to withdraw treatment, the nurses mediated and coordinated the family meetings. The different roles of the nurse were highlighted by Adams *et al.*'s (2011) study which found that the intensive care nurse acts as a mediator, information broker and advocate in end-of-life care during withdrawal of treatment in the ICU.

During the observation phase of this study, once the decision had been made to withdraw treatment from the patient, the nurse contacted the patient's family to arrange a private meeting where the decision to withdraw treatment was discussed and shared with the family in open, honest dialogue. The nurses informed me that they acted as information brokers between the family and doctors and often answered further questions posed by the families after the meeting. The nurses also stressed the importance of informative end-of-life meetings with the patient's family in order to discuss the decision to withdraw treatment. This role was highlighted by Abbi:

*...it is important that the family understand the reason for the decision
...I like to stay with the family after the consultant has finished
discussing the decision with them and ask them if there anything else
they want to ask? (Abbi)*

The findings from Lautrette *et al.*'s (2007) study suggested that by adopting good communication and listening strategies with families, the burden of bereavement was lessened. The issue of talking less and listening more during the meeting when the family were informed of the withdrawal decision was also highlighted in Seymour's (2001) seminal work. Seymour's (2001) study proposed that clinicians and nurses should explain and provide timely clinical prognostic information in order to support the family in coming to terms with the patient's poor prognosis. The findings from my study reflected continual family support throughout the patient's dying trajectory and during the transition from curative to palliative care.

In this study, the roles of the nurse were illustrated by the following comments from Efa and Uriah during the interviews:

...the nurse usually assesses the family dynamics and is the link to the medical team in order to help the family to resolve any conflicts and address any unanswered questions about the decision to withdraw.
(Efa)

...currently the nurse's role in ICU includes both a curative and palliative focus especially with the amount of withdrawals that we do.
(Uriah)

It was evident from both the observations and interviews that nurses who had experience in intensive care nursing were more adept and comfortable with the process of withdrawing treatment. This, however, did not make it easier for them to accept the fact that there were no further treatment options left to offer the critically ill patient. Previous nursing experience facilitated a sense of knowing the patient which was a result of the nurses' expertise and intuition. The literature suggests this concept of knowing necessitates expertise gained from experience in intensive care nursing practice (Crocker and Scholes, 2009). The intensive care literature explained that experienced nurses had developed 'knowing in action' or 'embodied knowledge'

which enabled them to care for patients' physical, emotional and psychosocial needs (Seymour, 2001). In this way, nurses were able to care for patients in an intuitive and expert manner, even when the patient was not able to communicate verbally with the nurses due to the sedative and analgesic therapies and aphonic state due to an artificial airway which was *in situ*. Benner *et al.* (1996) argued that emotional involvement was a key aspect of understanding and responding to the needs of the patient and the family (Seymour, 2001).

One participant clearly expressed the issue of previous experience relevant to withdrawing treatment:

...you know from previous experience that to continue treatment is merely prolonging the inevitable, if the patient does not respond to maximum therapies, there is very little more we can do or offer.
(Ardelle)

7.3 Withdrawing treatment

Prior to withdrawing treatment, the nurses informed me that they had a clear plan for the impending withdrawal of treatment, and a contingency plan as well for any complications which may arise during the withdrawal process. This plan included the withdrawal of ventilation, inotropes and other life-sustaining therapies. Once this was in place, the emphasis was on the patient's comfort and supporting the family. Managing end-of-life care in the ICU required a dramatic shift in nurses' attitudes and interventions, from an intensive rescue focus of care to intensive palliative care (Faber-Langendoen and Lanken, 2000). Once the decision to forgo treatment was made, the focus was on assessing all treatments applicable to the patient's end-of-life care and eliminating any unnecessary interventions.

Meticulous planning and sensitive decision making by nurses in the management of withdrawing treatment from critically ill patients was imperative, as a number of studies indicated that the fewer difficulties the patient experienced during the dying

trajectory, the greater the likelihood of the death being perceived positively by the family and the nurse (McNamara, 2001; Hopkinson *et al.*, 2003; Costello, 2006). This was evident in the findings from the interviews where the majority of participants preferred to keep the patient on the ventilator during the withdrawal process rather than perform terminal extubation. Terminal extubation often occluded the patient's airway and caused distressed breathing and noisy dying.

Level 3 intensive care patients were commonly unable to communicate and thus manifested themselves through their bodies, and it was through the body that a relationship was formed between the nurse and patient (Vouzavali *et al.*, 2011). Due to the sedative and analgesic therapies necessary to keep a patient comfortable whilst on a mechanical ventilator, the patient was not only in an induced coma but also aphonic. End-of-life care demands the same attention to detail, critical thinking and compassion that is required for critically ill patients who are expected to survive (Faber-Langendoen & Lanken, 2000).

Mohammed and Peter (2009) believed withdrawing treatment from critically ill patients may be viewed as a social performance that draws a distinguishable line between a rescue and a comfort focus of care. From a nursing perspective, caring for the dying patient goes hand in hand with caring for the patient's family. During the interviews, the participants discussed how various therapies were withdrawn sequentially during the patient's dying journey and how caring for the patient was redirected to supporting the family. The family were prepared for the withdrawal of treatment procedure and informed of what to possibly expect during the patient's dying trajectory. In addition, nurses reassured the family that the dying patient was pain free and comfortable in an attempt to help the family to find meaning in the death of their loved one. The intensive care unit where the study was conducted

encourages families to seek religious and spiritual support prior to the commencement of the withdrawal process and even after death.

Ziggy, who had eight years of intensive care nursing experience, described his experience prior to withdrawing treatment:

...after we broke the bad news, I remained afterwards and asked the family if there is anything they don't understand ...is there anything they would like me to go through and gave them the opportunity to ask questions ...usually there are questions and then I described how I would go about withdrawing the various. (Ziggy)

Ziggy continued:

...the important thing is to make sure the palliative stuff is in place ...you know the sedation and analgesia, that the patient is pain free and comfortable".

Nurses become accustomed to the appearance of the critically ill patient within this backdrop of invasive technology aligned to advanced care. Their training is conducted within clinical practice through a mentorship system. Novice nurses conduct the actual withdrawal of treatment autonomously after acquiring some experience in the clinical practice arena under the supervision of more experienced nurses. During the withdrawal process, the nurses are usually supported by their peers, team leaders and charge nurses. This was illustrated by the following comments from Ziggy and Ardelle:

...early on in my career I have had very good role models ...really good people who have taught me how to provide a good, dignified death in an ICU. (Ziggy)

I was really frightened the first time I had to withdraw the treatment myself but thankfully my team leader and charge nurse were nearby. (Ardelle)

Uriah, a senior nurse, highlights the importance of peer support during the withdrawal process:

...it is so important to make the right decisions at times like these ...and there is no text book to guide you ...and to be supported by your fellow nurses. (Uriah)

I noticed that time constraints within clinical practice often prevented nurses from undergoing a formal or supervisory debriefing session after the patient's death in the ICU. Informal debriefing usually occurred through mechanisms of peer support at the bedside or in the staff restroom.

I interviewed eight participants who collectively mentioned that withdrawing treatment from a critically ill patient followed a specific pattern of events or processes which they had observed and learnt from experienced nurses they had worked with in the ICU. The decision to withdraw treatment was discussed and finalised during the ICU morning round. The nurse caring for the patient then notified the family that their presence was required in the ICU and a meeting was arranged between the family, consultant and nurse at a designated time. At this meeting the decision to withdraw treatment was discussed and the patient's dying trajectory was explained. Unnecessary equipment was removed from the patient's bed space to allow easy access for the family and the curtains were drawn around the bed. The nurse then ensured the patient was presentable to the family, which often necessitated washing the patient with a change of clean linen. The concept of washing the patient prior to withdrawing treatment was evident in the interviews, as five out of the six participants mentioned that they washed or tidied up the patient routinely prior to withdrawing treatment. This was done out of respect for the patient and family, but also to show the family that the patient was cared for.

Ritual defines part of the culture of critical care nursing and strengthens the profession whereas ritualistic behaviour, on the other hand, is the carrying out of a task without thinking it through in a problem-solving manner according to several authors (Holland, 1993; Driver, 1998; Catanzaro, 2002). Ritual appears to be an

integral aspect of critical care nurses' work, their culture and the ICU environment where these practices serve to reassure nurses that they are providing the best care possible for the dying patient (Shorter and Stayt, 2009). Indeed from my personal experience in both southern and northern hemisphere countries, the process of washing the patient prior to withdrawing treatment may indeed symbolise the nurses' acceptance of the patient's impending death.

The washing of a patient prior to withdrawing treatment was echoed during the interviews by the following comments from Uriah and Abbi:

I like to make my patient really snug and comfortable and cared for. I can't imagine withdrawing on a fellow who has not had a shave ...you know what I mean? ...looking all haggard lying in the bed ...that's not right. (Uriah)

...then I wash the patient because there is no time during the withdrawal phase to do this ...you know if they soil themselves ...and when I do the last offices I wash the patient again ...but it is also good for the family to see that we care for our patients. (Abbi)

Next, planning the sequence of therapies to be withdrawn was important as the nurse was acutely aware that the patient and family would need support during the dying trajectory. The sequence of therapies to be withdrawn varied according to the particular patient's critical illness profile and the extent of the supportive therapy *in situ*. The nurse's decision making relevant to the actual withdrawal process was conducted with the family in attendance and occurred within the patient's bed space behind the closed curtains:

The withdrawal of treatment occurs in stages ...from the discussion regarding withdrawal of treatment then reviewing that everything has been done for the patient that could be done, to breaking the news, to the actual withdrawal of therapies (Uriah)

During the patient's dying trajectory, the nurses remained vigilant next to the family, either behind the closed curtains or just outside the curtains.

Abbi and Efa each summarised their account of how they withdrew treatment during the interviews:

...we withdraw treatment in a certain way which we have learnt or witnessed in our practice from our seniors ...first the haemofilter, then the inotropes and lastly, the ventilator ...we need to stay focussed on our decisions, what to withdraw next and so on ...you have to get it right, there is no room for mistakes. (Abbi)

...the visual appearance of the patient was the same as what they (the family) had got used to but the oxygen percentage was decreased dramatically. And the family were witness to the care that was being given during the withdrawal ...it seems to always follow a certain pattern ...it occurs in stages ...from the discussion regarding withdrawal of treatment, then reviewing that everything has been done for the patient that could be done, to breaking the bad news, to the actual withdrawal of therapies. (Efa)

Efa continued by saying:

...haemofiltration was the first therapy to be discontinued and this was done before the family came in to witness the withdrawal ...next I withdrew the inotrope support with the family watching ...this I did by merely switching the syringe drivers off quietly. It was important to gather all the family around the patient's bed space and be there with them ...you know this is the beginning of the end. (Efa)

Nurses who work in the ICU conduct their characteristic activities using equipment and artefacts within a cultural tradition which represents what Holland (1993) refers to as the accumulated decisions of the nursing group. It includes the human interactions and behaviours within this complex milieu, the material culture and cultural tradition. The dynamic, ever changing culture of the ICU encapsulates a learned set of shared guidelines, beliefs and behaviours through which nurses come to know how to live in their own social group (Holland, 1993).

Dylan, a junior nurse who had worked in the ICU for a few years, provided a sensitive account of how he managed withdrawing treatment in a particular patient:

Err ...I made sure the patient was comfortable from a sedation and pain aspect and also from a ventilator point of view. I wanted to make sure the family was aware of what was going on and what was going to happen. Me personally I always let the patient know what is going on

and what is going to happen ...irrespective whether they can hear anything or not, I always like to inform my patient what is going to happen in the politest kind of manner ...to be honest. (Dylan)

Withdrawal of treatment as managed by British nurses may aid expression and reinforce the shared values and beliefs of the nursing group in the ICU, thus creating a sense of group identity and social bonding. What I am arguing is that the withdrawal of treatment is not a ritual, but the actions surrounding and embedded within it may be viewed as a ritualistic practice.

Suominen *et al.* (1997) believe the technology used in the ICU provides the tool for seeking meanings out of critical illness, dying and death, whereas ritual serves as a social defence system protecting nurses against the anxiety that is caused by human suffering. Seeking meanings during times of crisis and stress, for instance during the process of withdrawing treatment, nurses may pursue rituals that comfort them during this intense and traumatic situation (Chambers and Curtis, 2001).

In the ICU where the study was conducted the medical and nursing personnel held a memorial service for the deceased patients and their families. I was invited to the annual memorial service by the nurses during the observation phase of my study, and was deeply moved by this heart-rending event filled with compassion and empathy. I believe this service proved to be a cathartic experience for all in attendance, the families, friends and intensive care personnel alike. This yearly event places the patient's death, which is seen as a routine occurrence in the ICU, within a broader human context, thus assisting personnel to seek meaning out of the extraordinary death of a patient which has occurred in the 'ordinariness' of the daily activities of the intensive care unit and culture.

The following scenario describes the timeline of the withdrawal of treatment process from my observation in the field:

Setting the scene - despite maximum medical therapy and technological supportive therapy for multiple organ failure, the patient's condition has steadily deteriorated rather than improving, and she has not responded to the supportive therapy administered. The secretary explains that each patient's vital signs are apparent on the central computer at the nurses' station. I am impressed by her knowledge and insight as she explains what each continuous tracing and value signifies, and appears to have insight as to what is normal and what is abnormal. These rows of luminous green numerical values and tracings for each patient cascade across the monitor screen highlighting a life which exists beyond this myriad of wires, tubes and machinery attached to the patient. The identical tracings and values are reflected on the monitor above the patient's bed space.

Closing the curtains - the curtain is drawn around the patient's bed space which the nurse tells me is to maintain patient privacy, especially when the staff are caring for the patient or assessing the patient. Constant hissing and clicking sounds are audible from the patient's bed space. The nurse informs me that these sounds are coming from the mechanical ventilator and the renal haemofiltration machine.

Decision time regarding withdrawing treatment - the curtain is drawn around the patient's bed space and a flurry of voices may be heard from behind the closed curtain now. This is followed by a discussion which takes place at the foot of the patient's bed but outside the curtain, involving all the staff present. The nurse caring for this patient and the ICU secretary are my key informants on this particular day of observation. I later learn from the nurse that the discussion which occurred at the foot of the bed, involved the team discussing the ethical and moral issues, physiological indicators, current clinical profile and prognosis pertinent to the patient, and the rationale for not escalating or continuing further treatment. Although the discussion occurs in low voice tones, it is still audible. It is apparent that the intensive care personnel are actively contributing towards and are engaged in the debate and discussion. The team then enter the patient's bed space behind the closed curtain again, but further discussion is no longer audible. The team emerge from behind the closed curtain, which is drawn back slightly by the nurse caring for the patient, and the consultant busily writes on the documents at the foot of the bed.

Informing the family - the morning intensive care assessment round continues as the team then make their way to the next bed space to review the next patient. The nurse informs me, after the team have moved to the next patient's bed space, that the consultant has documented his decision to withdraw treatment in this patient today. She mentions that the consultant is responsible for making the final decision with regard to withdrawal of treatment and that it is legally binding to document this decision clearly on the patient's charts. The rationale behind this decision is based on the ethical principle of futility in agreement within the multi-disciplinary intensive care team. She then goes about her work in a quiet manner, but appears rather subdued and has a sombre look on her face. The decision has been confirmed and the nurse informs me that she will now notify the patient's family to come in so that the consultant may break the news to them. Next she will prepare the patient and the bed space (i.e. remove all unnecessary equipment from the bed area) for the impending withdrawal of treatment.

Preparing the patient and the family - in contrast to the hive of nursing and medical activity prior to the morning round, there appears now to be a sudden lull and quietness surrounding the patient's bed space, after the team continue with the

intensive care morning round. The mood throughout the ICU appears sombre; even the ICU secretary is less talkative. It is somehow apparent that the personnel are aware of the impending withdrawal of treatment in this particular patient. The nurse walks over to the nurses' station and conducts a telephonic conversation with the patient's family informing them that their presence is required in the ICU. She returns to the patient's bed space and spends some time talking to the nurse in the adjacent bed space. The secretary tells me she is handing the patient over and the other nurse 'will keep an eye' on her patient while she has her morning break. The nurse then exits the unit for her morning break. After a short while, she returns from her break and closes the curtain, with another nurse in attendance. Their voices are audible behind the closed curtain and it appears that they are explaining things to the patient. The second nurse exits the bed space carrying what appears to be soiled bed linen. The patient's nurse emerges several times after this, collects two blue plastic chairs and enters behind the closed curtains. A little later, she collates some paperwork from the nurses' station and takes this to the patient's bed space.

Arrival of patient's family - the curtain surrounding the bed space will remain closed throughout the procedure of withdrawal of treatment and the patient's subsequent dying trajectory.

After about an hour, the front door buzzer of the ICU heralds the arrival of the patient's family. The ICU secretary goes over to the nurse behind the curtain and quietly announces that the relatives of the patient have arrived. The relatives (a middle aged man and woman) hurriedly enter the ICU and appear nervous. They are greeted by the nurse at the patient's bed space. She speaks to them in a caring and friendly manner, ushering them into the bed space behind the closed curtain. After a while, she emerges and disappears for a few minutes. On her return is followed by the consultant.

Supporting the family - you are not alone - together they usher the relatives out of the ICU. The ICU secretary informs me they have been taken to the private counselling room within the ICU complex where the news is broken regarding the decision to withdraw treatment and the patient's impending death is discussed. The consultant, the nurse and the relatives return to the patient bed space once again, where the consultant proceeds to join the multi-disciplinary team on the ICU round. The female relative is supported by the nurse as the nurse links her arm with the relative. They are behind the closed curtain again. Soft crying and muffled voices are audible from the patient's bed space.

The dying experience unfolds - this scenario of soft crying and muffled voices continues for the next hour. No one leaves the bed space during this time. The nurse stays with the family at the patient's bed space throughout this time behind the closed curtain. Only the hiss of the ventilator is now audible. I glance at the monitor screen at the nurses' station and notice that the patient's numerical values have decreased, especially her heart rate. The rest of the ICU personnel continue with what appears to be their normal daily activities with the occasional bonging of alarms, telephones ringing at the nurses' station, and the ICU entrance buzzer heralding the arrival of internal and external visitors. Throughout the withdrawal of treatment, there is a steady flow of people entering and leaving the ICU, some with stethoscopes hung around their necks but all dressed in plain clothes. Several trolleys are wheeled into the ICU, some heavily laden with linen stacked high, and others with a multitude of boxes varying in size which I am informed is pharmacy and general stock replacement. However, the noise level throughout the ICU appears quieter. Behind

the closed curtain, silence reigns at the patient's bed space and very little movement is apparent. The relatives' sobbing and voices talking in a low tone are now barely audible from behind the curtain. The decreasing numerical values on the nurses' station monitor reflect the unfolding scene taking place behind the closed curtain, signifying the patients dying trajectory. I notice that as the patient's heart rate slows down; the louder the sobbing behind the curtains becomes. The nurse's voice is audible at the start of the withdrawal of treatment, but her tone now appears softer as the patient's heart rate drops.

The death of the patient - suddenly the hissing noise stops, the crying is now audibly louder at the bedside for a short period of time and then there is silence. It is a strange silence – one can almost hear the silence. A few minutes later the sobbing relatives emerge from behind the closed curtain followed closely by the nurse, and together they exit the ICU. The nurse returns to the ICU after about 15 minutes and notifies the anaesthetic registrar of the patient's death. He then enters the patient's bed space to certify the patient's death. This is later confirmed by the nurse when I enquire about it. The relatives of the deceased patient do not come back into the ICU.

Opening the curtains - the curtain is only opened again after the nurse and another nurse have conducted the last offices and the patient's body is removed to the hospital mortuary. The nurse takes a break for 45 minutes in the staff rest room. I join the nurse in the staff rest room for my break where she remarks:

...well, we did everything in our power to sustain the patient's life. But unfortunately it was not good enough! ...anyway at least we could ensure a dignified and pain free death for the patient! It is just so hard for the relatives you know ...knowing there is nothing more we can do for the patient. I feel really sad when we withdraw treatment and sometimes it is difficult to not cry when you are with the relatives and everyone involved with the care of the patient feels a sense of helplessness and loss

Nurse's reflections on supporting a dying patient and family as treatment is withdrawn in the ICU - the nurse explains her role during withdrawal of treatment and the patients dying trajectory to me. She mentions her remit involves supporting the family and to ensure the patient is comfortable, pain free and has a dignified death. Once the consultant has confirmed and documented the withdrawal of treatment, the nurse caring for the patient prepares for and conducts the withdrawal of treatment. This is a nurse-led practice whereby the nurse's role is heightened by living the experience with the patient and the family, supporting them whilst actually conducting the withdrawal of treatment. We sip our coffee in silence, while I write my notes and the nurse blankly pages through a magazine and occasionally directs her attention to the plasma television screen on the wall. I ask her if she would like to talk about her feelings regarding the withdrawal of treatment, but she tearfully declines, saying:

...aw, it is just nice to be here [in the tea room] away from it all for a while, I know you know what it is like, sometimes it helps just to know someone understands what we intensive care nurses go through.

And the nurse's daily work in the ICU continues - the nurse enters the unit again from her break and helps another nurse with a new admission, a patient who

has arrived from recovery room. She disappears behind the curtain drawn behind the patient's bed space. From the time the multi-disciplinary team leave the patient's bed area, the following 2 hours and 40 minutes of events appear to be time-lapsed in an unknown, yet shared transitional journey. (Extract from field notes)

The patient's dying journey to death has unfolded and shifted from a curative, rescue focus to an intensive palliative perspective – from a life event which encompasses technological and advanced supportive measures to sustain life at all costs, to attempting to mimic natural dying, an (un)certain death at an unknown time. A patient has died, a family and a nurse face their separate bereaved states and life continues in the ever-changing world of the ICU.

In the UK, the legalities relevant to withdrawal of treatment in critically ill patients in the ICU and intensive care bed resources influence the limitation of ineffective therapies. Historically, critically ill patients previously died despite maximum technological support, whereas patients are more likely to die in the future following withdrawal of treatment (Luce and Prendergast, 2001).

The mortality statistics in the ICU where the study was conducted for the years 2010 to 2012 are reflected in a tabulated format below:

Table 3: Statistics of incidence of deaths in the ICU where the study was conducted

Year	Total deaths in ICU/total number of admissions	Deaths following withdrawal of treatment
2010	165 (20.4%)	95 (57.8%)
2011	165 (20.7%)	91 (55.2%)
2012	163 (21.4%)	85 (52.1%)

The statistics from this table suggest more than half of the deaths which occurred in the ICU were following the decision to withdraw treatment.

7.4 Summary

Critical care nurses enact different roles when caring for the critically ill patients during withdrawal of treatment and at end-of-life. Previous experience of withdrawing treatment, together with advanced nursing knowledge and patient-centred caring, emerged as important characteristics relevant to nurse involvement during the decision making process and planning the patient's end-of-life care.

Nurses deliver holistic care to meet the individual needs of each critically ill patient, which necessitates constant attention, and a sense of closeness and belonging for nurses who remain at the patient's bedside throughout the day and night. In a sense, the nurse becomes emotionally a part of the patient and the family's world.

The therapeutic use of self, temporality and spatiality are integral aspects of intensive care nursing. Nurses experience deep emotional sadness during the practice of withdrawing treatment from patients. A nurse's emotional involvement appears to be a key aspect of understanding and responding to the needs of the patient and the family.

Withdrawal of treatment appears to follow a certain format from the time the decision is made until the nurse-led practice commences. During the transition from a curative to a palliative focus of care, the nurse redefines the patient's care and redirects it in supporting the family during the patients dying trajectory.

British nurses manage withdrawal of treatment, which may reinforce their shared values and beliefs in the intensive care environment.

I have included a reflexive description taken from my field notes which describes a scenario where treatment was withdrawn from a patient in the ICU. The changing roles of the nurse are apparent in the transition from a curative focus to a palliative focus of care, managing the withdrawal of treatment and the patients dying trajectory

whilst supporting the family, and finally returning to care for another patient within a curative focus of care.

Chapter 8 discusses the third central theme of the shared experiences in the journey towards death.

Chapter 8: Shared experiences in the journey towards death

8.1 Introduction

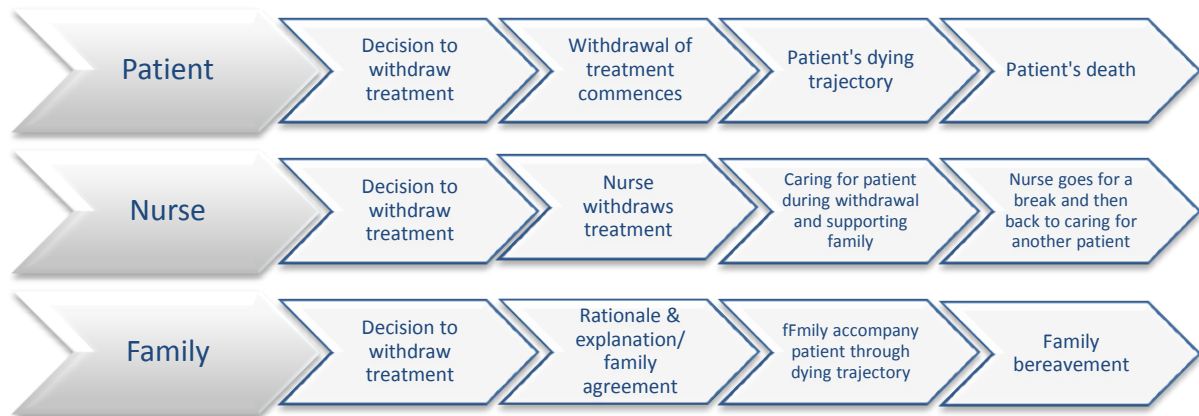
This chapter discusses the final central theme which emerged from the findings of the study, which is the shared journey to death as experienced by the patient, the nurse and the family. Sub-themes relevant to a parallel journey to death and supporting the family are included in the discussion.

8.2 Parallel journey to death

The findings from observation and the interviews revealed that the patient, nurse and family experienced a parallel, shared journey from the time the decision was made to withdraw treatment, during the actual practice of withdrawing the treatment, through the patients dying journey until death. This journey was filled with caring compassion, empathy and support. Nurses redefined the patient's care from a curative focus to a palliative focus of care, and redirected patient care to support the family through this fraught and fragile experience. The findings from the interviews and the observations substantiate this notion of a parallel-shared journey to death. The patient's journey ends in death; the family's journey in bereavement; and the nurse's journey ends in conducting the dead patient's last offices, followed by a break in the staff restroom only to return to the ICU to care for another critically ill patient and revert back to a curative focus of care.

Figure 4 (below) indicates the concept of a parallel journey of the patient, nurse and family following the decision to withdraw treatment.

Figure 4: Concept of parallel journey to death



During the fieldwork, I became aware that the anguish of a critical illness in the ICU was more than just a physical experience for the patient, their family and the nurse caring for the patient. The essence of this caring relationship, which usually developed during the patient's illness embodied human, social and spiritual dimensions of holistic care. Nurses were key agents in assisting the patient's family to experience the transition from cure to comfort during treatment withdrawal, and tried to ensure a respectful transition treated with sensitivity, care and compassion. In his book *Constructing Death: The Sociology of Dying and Bereavement* (1998) Clive Seale offers insight into human social bonding in the face of death as a continual practice which infiltrates everyday life. I believe the nurses were instrumental in creating a conducive caring and supportive environment for the family during the patient's dying. This environment encompassed the development of a close relationship of trust and respect between the nurse and family. It certainly appeared to be rather a unique relationship where the nurse almost became a part of the family, and from an emotional perspective shared the anguish and sadness experienced by the family. Jethro's comment illustrates this point:

I think the nurse shares the patient's dying process with the family
(Jethro)

The nurse's presence during this life event in the intensive care environment bridges the distance between the silent sedated patient and the distraught family. Patients and families feel comforted and nurtured by nurses who experience ease with the dying trajectory, who do not shrink back from honest expression of grief, loss and uncertainty, and who present themselves with steadiness in the face of the patient and the family's fear and anxiety about dying and death (Levy, 2001). During the fieldwork I noticed that the nurses spoke to their patients as if they were awake and able to respond and answer back. When I questioned the nurses on what I had observed, most of the nurses informed me that they believed that the sedated silent patient could hear them and that in their view the patient was still able to communicate, even if it was through their body especially the eyes.

I would argue that in my study the concept of social death was not apparent. The nurses spoke to their patients as if they were able to comprehend and answer back, and encouraged the family to do so as well. Nurses therefore acknowledged the patient's social presence, although in reality the patient appeared to be in a state of social limbo due to the analgesic and sedative therapies administered. Nurses were very proud of the care they delivered to the dying patient and recognised the patient's social significance (Seymour, 2001)

This was illustrated by the following comments from Dylan:

*I talk to my patients as if they are awake ...am sure they can hear you
...have seen the patient's eyes following me around as I work with them
...just being there and caring for the patient is important to me...*
(Dylan)

In this study, as the various therapies were withdrawn during the patient's dying, the nurse guided the family through the patient's dying trajectory by explaining, supporting and often just being there for the family. Nurses tried to prepare the family for the patient's dying and subsequent death, and reassured the family that the dying

patient was pain free and comfortable in an attempt to assist the family to find meaning in the death of a loved one (Rocker *et al.*, 2010).

During the fieldwork, it was apparent that the nurses were open to additional supportive measures to comfort the anguished family, such as religious and spiritual support and guidance. The nurses experienced what appeared to be meaningful and intimate relationships with the patient and family. I recall several family members giving the nurses kind and thoughtful gifts like doughnuts, cookies and cakes. There appeared to be a reciprocal and healthy relationship of trust and respect between the nurses and families. Bach *et al.* (2009) suggest that one of the most fundamental roles critical care nurses play in providing emotional support to families and patients is being present at the bedside, providing comfort, a caring touch and a listening ear.

Critically ill patients were central to nurses' meaning-making process and role perception, and the participants informed me that the use of the therapeutic self was important when communicating with their patients, especially the patients who underwent mechanically ventilated. It was apparent that caring for these critically ill patients triggered emotions of compassion and concern in the nurse, which I would argue was the basis for the development of the nurse/patient relationship in the ICU. This caring and compassion was expressed by the following comments from Dylan:

I stayed with him throughout the WOT and held his hand as I did not want him to die alone. I remember this particular case well as it really had an impact on me. It was really sad but fortunately I was there with him. I spoke to him and at other times just sat there with him. I acted as his family in my role as a nurse ...so that the patient knew someone was there for him (Dylan)

The findings of this study suggest that as the nurse withdrew treatment from the patient, the nurse and family entered a shared journey to death with the dying patient whereby the nurse, patient and family all transitioned the state of betwixt and between, life and death. An uncertainty surrounds the boundary between life and

death in the ICU, a situation which is further complicated by the fact that life, in this instance, necessitates supportive therapies from various types of invasive technology (Philpin, 2007).

During a critical illness the patient has undergone the preliminal rite of passage by admission to the ICU and transitions the liminal stage during the withdrawal of treatment process. During this liminal stage, the patient enters a 'betwixt and between' state of sustained life and death; being kept alive with the supportive therapies from various types of invasive technology, but transitioning into the dying stage towards death. The concept of liminality originates from the work of van Gennep (2004) and subsequently Turner (1969; 1967) on ritual and rites of passage. Van Gennep (2004) proposed that the life of an individual in society was a series of passages from one age to another, and typical rites included life events such as birth, marriage and death (van Gennep, 2004). Rites of passage are divided into rites of separation (preliminal), rites of transition (liminal) and rites of reincorporation (postliminal) (Blows *et al.*, 2012).

Nurses are positioned on the threshold between life and death as they withdraw treatment and manipulate sedative and analgesic infusions to maintain a state of social inertia or, as Turner (1969) suggests, a state of social limbo. Death is omnipresent; the time, however, is unknown. The outcome of this tripartite parallel journey to death results in a social change where the patient dies, the family enter the bereavement period, and the nurse's involvement with the patient ends with the delivery of the last offices to the patient.

Ciccarello (2003) advocates nursing presence during withdrawal of treatment care is a simple but powerful intervention. In an attempt to overcome the dehumanising aspects of dying in a technological milieu, nurses reconnect the patient with their family by the development of trust between nurses, doctors and the patient's family

and by accepting the inevitability of death in realistic terms (Fridh *et al.*, 2009). The art of creating comfort and compassion in the midst of advanced technology during dying and death in the ICU has a direct impact on the memories that family and nurses take with them after this sad life event. Pattison (2011) concludes that where critical care nurses engage and are involved from the time the decision to withdraw treatment is confirmed until the death of the patient, it can be a potentially satisfying, albeit sad, experience. The following comment captures the essence of intense caring and the sense of loss that the nurse feels during this fragile journey to death:

...after the patient has died, I conduct the last offices and then after a short break, I will be back to care for another level 3 patient ..just need a little more time to deal with my sadness... (Jethro)

8.3 Supporting the family

Throughout the interviews and observation in this study, the participants stressed that caring for the dying patient as treatment was withdrawn went hand in hand with caring for the patient's family. Supporting the family during the withdrawal process was a profound and unanticipated theme which emerged from the findings from this research. Additionally, the participants were acutely aware that there was no room for errors during this fraught and fragile time of dying and death in the ICU.

As the nurses withdrew the life-sustaining therapies from the patient, the nurse caring for the patient redirected this care to the family in a supportive manner. Most participants mentioned that it was a privilege to accompany the patient during their dying journey together with the family. Caring for the dying patient and supporting the family through this dying process until death was a life event where the nurse could not afford to get it wrong. Jethro and Efa clearly expressed this issue in the interviews:

the nurse not only has to withdraw treatment in the patient but also support the family though the dying process, which is challenging as we only have one chance to get it right – you know to ensure a pain free

and peaceful death for the patient and to be there and support the family so they are not alone. (Jethro)

...the patient's family were with her and held her hand and in turn I supported them all during her dying as we withdrew the treatment. (Efa)

The essence of the caring relationship which usually developed between the patient, the nurse and family during the patient's intensive care journey embodied human and social dimensions of holistic caring. This aspect was summed up by Ardelle:

I feel sad for the family but also for myself ...during withdrawal, I feel that I am sharing the dying experience with both the patient and the family ...they are going through this emotional journey next to the person they love and somehow we as nurses feel and share their pain because we are losing a patient we have cared for during a critical and intense journey. (Ardelle)

From the findings it became evident that from the time the news was announced to the family concerning withdrawal of treatment until the patient's death, the nurse played a pivotal role in assisting the family to come to terms with the decision and the patient's subsequent journey to death. Families of dying patients following withdrawal of treatment often experience emotional distress and anxiety, a tendency towards denial of death and difficulties in understanding medical information (Rocker *et al.*, 2010). Participants suggested that they devoted their time in supporting the family to understand the patient's poor prognostic outcome and by explaining what to expect during withdrawal of treatment, the patient's dying and after death.

Several participants explained how they encouraged the family to confront the patient's impending death by holding the patient's hand and talking to the patient during the dying process. Efa and Dylan illustrate this point:

...I turn down the lighting around the bed, make sure the patient's arms and hands are available for the family to hold, and I always encourage

the family to speak to and touch the patient and hold the patient's hands ...to say their goodbyes. (Efa)

Err ...I just continually supported the family throughout the dying process ...did not say much, just stayed with them ...and asked them to hold the patient's hand (Dylan)

During my field work it was apparent that initially families perceived the advanced technology and surrounding intensive care environment with a degree of fear of the unknown, especially with regard to the unfamiliar sights, sounds, smells and penetrated patient bodies. Families became aware with time that this intensive technology and advanced caring sustained the patient's life, which was often in a precarious balance, as they tried to deal with a fraught situation and an emotional rollercoaster journey of waiting and hope. I observed their reactions whenever a machine alarmed. The family would become distraught as if fearing the worst case scenario and anxiously looked at the nurse for a reaction. The patient's life appeared to be embedded within this invasive technology. Nurses soon educated the family regarding the vast array of technological bodily intrusions in an attempt to minimise the family's anxiety, and simultaneously increase their understanding of the intensive care culture.

Vouzavali *et al.* (2011) propose that nurses perceive the handling of the patient's body and fluids at a deep level, as an approach to a patient's soul, thus extending the connection beyond the body to encompass psychological and spiritual dimensions. I observed that nurses became intertwined in the life of every patient and the patient's family, and a relationship usually developed built on mutual respect, honesty and communication. This relationship was encapsulated by Jethro's response during the interview:

it is hard not to be affected personally whether it be family members or the patient ...because sometimes you have nursed the patient for a

long time and have a close connection with the family and the patient ...you get to know them so well ...you become a part of them. (Jethro)

In the interviews and throughout the field work it was evident that, from an emotional perspective, the nurses experienced their own professional emotional turmoil and sadness when caring for dying patients and families following the decision to withdraw treatment. I believe the interviews afforded the participants an opportunity to be listened to and some participants mentioned that it was cathartic.

The nurses experienced sadness and grief as they withdrew treatment:

...I feel so sad when I withdraw treatment but at least I try to offer dignified dying for the patient and am there for the family. (From field work)

The art of creating comfort and compassion in the midst of advanced technology during dying and death in the ICU has a direct impact on the memories that family and nurses take with them after this sad life event. Uriah and notes from the field work highlight this aspect:

...withdrawing treatment creates a sense of grief for the nurse caring for the patient ...I obviously don't feel the same degree of grief that the family feel but although it is different it remains a sense of sadness and grief. (Uriah)

...I feel a deep sense of human loss with regard to withdrawing treatment in my patient ...I can identify with the family ...the only thing I am sure of during a time like this is that I was there for the patient and the relatives ...it is always so sad ...despite doing our best for the patient. Oh well, life goes on irrespective! (From field work)

Pattison (2011) concludes that where critical care nurses engage and are involved from the time the decision to withdraw treatment is confirmed until the death of the patient, it can be a potentially satisfying, albeit sad, experience. Bach *et al.* (2009) suggest that one of the most fundamental roles critical care nurses play in

providing emotional support to families and patients is being present at the bedside, providing comfort, a caring touch and a listening ear.

The following comment perhaps captures the essence of intense caring and sense of loss that the nurse feels during this fragile time of withdrawing treatment from a critically ill patient:

...afterwards all you are left with is an empty bed... (Abbi)

8.4 Summary

The participants' strong emphasis on shared experiences towards death and supporting the family in this study were unanticipated and unexpected.

The place was the ICU, where the scene was set around an unconscious, critically ill patient who no longer responded to maximum biotechnological support. Curtains sheltered the vulnerable patient from the rest of the intensive care milieu and the patient's bed space served as a protected and private area where dying and death would ensue. There were different players enacting their respective roles as doctors, nurses and family members. The patient was silent due to a sedative and analgesic induced state. Once the decision to withdraw treatment had been made, the family's attendance at a meeting was requested and the family were notified of the decision. The nurse would prepare the setting and patient, create an appropriate environment for dying, and support the family as the withdrawal of treatment unfolded. The close, intimate relationship of mutual trust and respect between the silent patient, nurse and the family is integral to this dying journey to death following the decision to withdraw treatment. Chapter 9 includes the conclusion and implications for clinical practice of the study.

Chapter 9: Conclusion and implications for clinical practice

9.1 Introduction

This chapter will offer a summation of what the findings mean regarding nurses caring for critically ill patients during withdrawal of treatment, and how the central themes may support nurses in the future and the implications for clinical practice. The data from the findings clearly indicate the importance of the patient's end-of-life care following the decision to withdraw treatment in the ICU and a shared experience in the journey towards death. Additionally, the findings emphasise critical care nurses' changing profile, where nurses redefine the patient care from a curative to a palliative focus during the withdrawal of treatment and end-of-life. This chapter also includes an overview of my professional doctorate journey as a practitioner researcher and later as an academic, and the significant impact this study has had on me personally and professionally.

9.2 Professional and personal impact of the professional doctoral journey

I commenced the professional doctorate as a practice development facilitator in critical care nursing and towards the end of the second year of the programmes taught element, my professional role changed as I entered academia as a lecturer. I recall during a particular session, the programme leader aptly describing the doctoral journey as an extremely challenging yet 'illuminating' experience. Reflecting on my journey, I would agree it has indeed been an illuminating element of my life.

From the outset, I embraced the realisation that this level of scholarly enquiry and advanced learning would require a high degree of self-discipline, motivation and zest. Maintaining the equilibrium between full-time work, part-time study and an active home life was no easy task. However, with time, accepting ownership for my doctoral

study actually complemented my existing inner motivation and the programme objectives became more comprehensible as the learning curve unfolded.

As I progressed through each year of my doctoral journey, I identified further skills required for developing a self-reflexive approach to the management of learning and the acquisition of research methodologies and professional expertise, to progress research in professional practice. This reflexive process initiated the critiquing of my own personal position and professional role within a range of theoretical, leadership, managerial and social constructs, and highlighted the knowledge and understanding necessary to conduct my own real world research.

It was evident that effective time management on my part would present a constant challenge throughout my doctorate. This journey of discovery has been fashioned by the sharing of knowledge, friendship, reciprocal learning and the opportunity to conduct research in clinical practice. Perhaps more importantly, this journey has offered insight into life and death. During the study I suffered the personal loss of a young family member who underwent withdrawal of treatment and I lost four dear friends who died from terminal illnesses. At times it was so difficult being involved with my chosen topic, collecting and analysing data and writing the thesis when I was experiencing and living my own bereavement.

Self-esteem and confidence sustained each other on this journey, and proved to require a process of constant renewal and a 'double edged' sword of self-exploration. Increased self-esteem and awareness facilitated increased confidence, allowing for further critical exploration and identification of future learning needs, with the prospect of developing new skills and academic credibility. The doctoral journey has developed my research skills and afforded me a deeper understanding of issues from a clinical practice and academic perspective, where I believe I can make a

contribution towards the existing body of knowledge pertinent to the topic and reflect on my own professional practice.

A personal electronic journal captured my feelings, experiences, thoughts and subsequent learning curve and journey throughout the years. Together with several memory sticks, it remained a trusted, reflexive informatics companion and silent blog. The journal helped me to focus on my internal responses to being a researcher and captured my ideas, fears, the impact of the research upon my personal and professional life and the journey of discovery.

Lee (2009) states the overall aim of the professional doctorate is to develop a realistic, manageable, exciting and stimulating focus for study, combining this with the application of appropriate research methods for professional practice. This research has added to my existing knowledge and clinical practice of critical care nursing, especially with regard to British nurses' experiences of withdrawing treatment from critically ill patients in the ICU. I believe I have been enriched by this doctoral experience as a professional, as it has developed my capability as an expert practitioner and researcher to contribute to the critical care nursing evidence base for practice, and also to improve the patient and family's intensive care journey through understanding the nurses' experiences. This doctoral journey of discovery has afforded me the opportunity to add to the existing body of knowledge pertinent to the patient's end-of-life care, and to the dynamic role of the nurse in providing this care and supporting the family during this emotive and sad life event.

Ultimately, I believe this research project has provided a significant contribution to my personal and academic life, in that I have learnt to appreciate and maintain optimism, commitment, adaptation to the unforeseen and to be comfortable with uncertainty.

9.3 Implications for professional practice

Given the findings from the study, the implications for professional practice include the following:

- Disseminate the findings from the research by publications, book chapters and conference presentations at a national and international level. This will ensure international exposure to this unique study and its findings in relation to caring for a patient and their family during withdrawal of treatment, as well as the role of the nurse during the end-of-life process.
- Encourage an ethos in the ICU where palliative care specialists are included and participate during end-of-life care activities in the ICU for instance, the inclusion of palliative care staff during withdrawal of treatment. This would be promoted through presentation of the study and its findings to all staff involved in that environment.
- Recommend that nurses nationally be supported during this withdrawal of treatment time by adopting formal debriefing strategies under the auspices of a specialist palliative care practitioner through the presentation of three monthly patient case study sessions (off site of the ICU complex).
- Recommend that palliative care skills and knowledge regarding end-of-life care be included in any continuing education, lifelong learning and post-registration educational programmes at all academic levels.
- Recommend that knowledge of palliative care skills required for patients' end-of-life care following withdrawal of treatment decisions in an ICU be included in appropriate pre-registration nursing programmes.
- Recommend that the cathartic practice of conducting an annual memorial service for intensive care patients who died in the ICU and their families be further explored as evidence of good practice by health care organisations.

The valued significance of this memorial service may have far-reaching benefits for intensive care staff, families of the deceased patients and the organisation as a whole. This practice lends itself to further research, which could explore the impact of this practice on intensive care nurses and the families of patients who have died in ICU.

9.4 Limitations and strengths

Limitations are inherent in all types of research and this study is no different. The sample comprised participants in the ICU who were British and of a white ethnic group. The sample size could be viewed as small so researchers cannot generalise about their research findings (Guba and Lincoln, 1985). Conducting ethnography in the nursing culture presents challenges when a researcher is attempting to become a 'cultural stranger', especially when questioning the assumptions of a familiar culture whose rules and norms have become internalised. However, not having worked in the particular ICU where the study was undertaken did offer me a certain degree of 'strangeness'. My doctoral supervision team also assisted with regard to this aspect by offering advice and direction as outsiders to the study. I have endeavoured to offer the reader an overview of my story and insight into the research journey as I conducted this study by acknowledging my own perspectives, previous experience in clinical practice and personal reflections throughout the thesis. I believe that the strengths of this study are entrenched in the uniqueness of its findings.

9.5 Uniqueness of findings

The uniqueness of this study's findings includes the actual topic chosen, the analytical framework and the results. The nurses' experiences, pivotal involvement and contribution to end-of-life care in the critically ill patient during withdrawal of

treatment are also unique. This participation commences from the time the decision making process begins until the patient's death, and finally ends with the patient's post mortem care. An additional unique feature from the study involved the shared journey of the patient, nurse and family to death. The patient, nurse and family all experience liminality, each reaching different outcomes. The findings also offer insight into how nurses support each other and the family, and especially how nurses manage the dying trajectory and the patient's death. This study's findings offer a contribution to the evidence pertinent in end-of-life care in the ICU setting.

9.6 Conclusion

Exploring the critical care nurses' experiences during the process of withdrawing treatment and providing palliative care offered insight into the cultural and clinical practices of the nurses, who played a key role during the initial decision making process, the actual withdrawal of treatment, caring for the dying patient and supporting the relatives until death. In summary a significant finding was the discovery of the shared journey towards death as experienced and intersected by the patient, nurse and family, as well as the nurse's pivotal adaptation from a focus of cure to end-of-life care. After the patient's death, the nurse cares for another critically ill patient where a curative focus of care would once again become a priority.

The frequency of death occurring following the decision to withdraw treatment from critically ill patients in the ICU is due to the availability of modern advanced technology thus sustaining patients' lives in the face of critical illness. The presence of the family during the patients' dying trajectory shifts the nurse's focus from the patient to the family, and is at the core of the nurses' end-of-life care work (Halcomb *et al.*, 2004). This study found that nursing practices conducted throughout the withdrawal process included providing comfort care to the dying patient whilst

simultaneously supporting the family, and aimed to offer positive and meaningful experiences during this emotive phase of life. The findings reflect the need for supporting critical care nurses during the patient's withdrawal of treatment and subsequent death on both an informal and formal basis.

Furthermore, the findings from this study contribute towards the current understanding and existing evidence of the nurses' experiences of end-of-life care in the ICU, and support the need for further research, especially on the process following the decision to withdraw treatment from the patient. Since many deaths in the ICU occur following the decision to withdraw treatment, decision making and end-of-life care are essential to improving patient and family outcomes. Nurses need to develop their skills and knowledge in order to make sense of dying and death in the ICU following the practice of withdrawing treatment. The inclusion of a palliative care specialist team could enhance the quality of patients' end-of-life care presently delivered. This will necessitate nurse education, good communication and information sharing with the family, and collaboration within the intensive care multi-disciplinary team and beyond.

Critical care nurses could influence the integration of critical care and palliative care at end-of-life, and thus enhance the journey to death for the patient, the family and the nurse withdrawing treatment. The ultimate aim would be to provide quality care at end of life in the best interests of the patient.

Conducting this study has proved to be challenging and inspirational, and I have endeavoured to offer insight into the nurses' experiences as they participated in this emotive and fragile life event. I firmly believe that patients' needs create this thirst for knowledge acquisition within us, as we strive towards improving their outcomes and critical care illness journey as both professionals and researchers.

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Appendices

Appendix A: Benton and Cormack (2000) critique framework

Questions to be asked of various sections of a research report	
Heading	Questions to be asked
Title	<p>Is the title concise?</p> <p>Is the title informative?</p> <p>Does the title clearly indicate the content?</p> <p>Does the title clearly indicate the research approach used?</p>
Author(s)	<p>Does the author(s) have appropriate academic qualifications?</p> <p>Does the author(s) have appropriate professional qualification and experience?</p>
Abstract	<p>Is there an abstract included?</p> <p>Does the abstract identify the research problem?</p> <p>Does the abstract state the hypotheses (if appropriate)?</p> <p>Does the abstract outline the methodology?</p> <p>Does the abstract give details of the sample subjects?</p> <p>Does the abstract report major findings?</p>
Introduction	<p>Is the problem clearly identified?</p> <p>Is a rationale for the study stated?</p> <p>Are limitations of the study clearly stated?</p>
Literature review	<p>Is the literature review up-to-date?</p> <p>Does the literature review identify the underlying theoretical framework(s)?</p> <p>Does the literature review present a balanced evaluation of material both supporting and challenging the position being proposed?</p> <p>Does the literature review identify the need for the research proposed?</p> <p>Are important references omitted?</p>
The hypothesis	<p>Does the study use an experimental approach?</p> <p>Is the hypothesis capable of being tested?</p> <p>Is the hypothesis unambiguous?</p>
Operational definitions	<p>Are all terms used in the research question/problem clearly defined?</p>
Methodology	<p>Does the methodology section clearly state the research approach used?</p> <p>Is the method appropriate to the research problem?</p> <p>Are strengths and weaknesses of the chosen approach stated?</p>

Subjects	Are the subjects clearly identified?
Sample selection	Is the sample selection approach congruent with the method to be used? Is the approach to sample selection clearly stated? Is the sample size clearly stated?
Data collection	Are any data collection procedures adequately described? Have the validity and reliability of any instruments or questionnaires been clearly stated?
Ethical considerations	If the study involves human subjects has the study received ethics committee approval? Is informed consent sought? Is confidentiality assured? Is anonymity guaranteed?
Results	Are results clearly presented? Are results internally consistent? Is sufficient detail given to enable the reader to judge how much confidence can be placed in the findings?
Data analysis	Is the approach appropriate to the type of data collected? Is any statistical analysis correctly performed? Is there sufficient analysis to determine whether 'significant differences' are not attributable to variation in other relevant variables? Is complete information (test value, degrees of freedom and probability) reported?
Discussion	Is the discussion balanced? Does the discussion draw upon previous research? Are the weaknesses of the study acknowledged? Are clinical implications discussed?
Conclusion	Are conclusions supported by the results obtained? Are the implications of the study identified?
Recommendations	Do the recommendations suggest further areas for research? Do the recommendations identify how any weaknesses in the study design could be avoided in future research?

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Appendix B: Literature searching strategy

No. Database Search term Hits

- 2 MEDLINE support*.ti,ab 656307
- 3 MEDLINE icu.ti,ab 17335
- 4 MEDLINE (intensive AND care AND unit).ti,ab 38591
- 5 MEDLINE exp INTENSIVE CARE UNITS/ 38841
- 6 MEDLINE *INTENSIVE CARE UNITS/ 11759
- 7 MEDLINE 3 OR 4 OR 5 68522
- 8 MEDLINE "end of life".ti,ab 6467
- 9 MEDLINE (death OR dying).ti,ab 335896
- 13 MEDLINE exp WITHHOLDING TREATMENT/ OR exp EUTHANASIA, PASSIVE/ 10802
- 18 MEDLINE DEATH/ 10222
- 19 MEDLINE (withdrawal ADJ4 treatment).ti,ab 4510
- 20 MEDLINE (withdrawal AND of AND treatment).ti,ab 20548
- 21 MEDLINE "withdrawal of treatment".ti,ab 566
- 22 MEDLINE (withhold* ADJ4 treatment).ti,ab 685
- 23 MEDLINE (withheld ADJ4 treatment).ti,ab 276
- 24 MEDLINE 8 OR 9 OR 13 OR 18 OR 19 OR 20 OR 21 OR 22 OR 23 372570
- 25 MEDLINE 2 AND 7 AND 24 1018
- 26 MEDLINE 25 [Limit to: (Age Groups All Adult 19 plus years) and English Language] 464
- 31 MEDLINE px.fs 527405
- 33 MEDLINE 26 AND 31 [Limit to: (Age Groups All Adult 19 plus years) and English Language] 81
- 34 EMBASE support*.ti,ab 502506
- 35 EMBASE icu.ti,ab 14578
- 36 EMBASE (intensive AND care AND unit).ti,ab 31305
- 37 EMBASE exp INTENSIVE CARE UNIT/ 27498
- 38 EMBASE 35 OR 36 OR 37 49340
- 39 EMBASE "end of life".ti,ab 3856
- 40 EMBASE (death OR dying).ti,ab 251985
- 41 EMBASE (withdrawal ADJ4 treatment).ti,ab 4069
- 42 EMBASE (withhold* ADJ4 treatment).ti,ab 483
- 43 EMBASE (withheld ADJ4 treatment).ti,ab 233
- 45 EMBASE exp TREATMENT WITHDRAWAL/ 3254
- 46 EMBASE exp DEATH/ 174899
- 47 EMBASE 39 OR 40 OR 41 OR 42 OR 43 OR 45 OR 46 369706
- 48 EMBASE 34 AND 38 AND 47 976
- 49 EMBASE 48 [Limit to: (Human Age Groups Adult 18 to 64 years or Aged 65+ years) and English Language] 444
- 50 CINAHL support*.ti,ab 92618
- 51 CINAHL icu.ti,ab 4705
- 52 CINAHL "intensive care unit".ti,ab 7932
- 53 CINAHL exp INTENSIVE CARE UNITS/ 12975
- 54 CINAHL 51 OR 52 OR 53 18097
- 55 CINAHL "end of life".ti,ab 4522
- 56 CINAHL (death OR dying).ti,ab 30664
- 57 CINAHL (withdrawal ADJ4 treatment).ti,ab 390

58 CINAHL (withh* ADJ4 treatment).ti,ab 191
59 CINAHL exp EUTHANASIA, PASSIVE/ 1906
60 CINAHL exp DEATH/ 14830
61 CINAHL 55 OR 56 OR 57 OR 58 OR 59 OR 60 43345
62 CINAHL 50 AND 54 AND 61 284
63 PsycINFO support*.ti,ab 294254
64 PsycINFO (icu OR "intensive care unit").ti,ab 1582
65 PsycINFO exp INTENSIVE CARE/ 1287
66 PsycINFO 64 OR 65 2081
67 PsycINFO 63 AND 66 424
68 PsycINFO "end of life".ti,ab 2460
69 PsycINFO (death OR dying).ti,ab 38590
70 PsycINFO (withdraw* OR withh*).ti,ab 25941
71 PsycINFO 68 OR 69 OR 70 65170
72 PsycINFO 63 AND 66 AND 71 69

The dregs from Medline (~400)
Everything from Embase (~450)
Everything from PsychInfo (~70)

Appendix C: Synopsis of summarised articles

Short Reference	Method	Sample Size & Characteristics	Main Findings/Salient Aspects of study
Holland, C. K. (1993) An ethnographic study of nursing culture as an exploration for determining the existence of a system of ritual. <i>Journal of Advanced Nursing</i> , 18: 1461-1470.	Ethnography as a method & description UK study	Group of nurses on a ward Cultural observation and interviews Researcher's emic and etic perspectives	Study explored nursing culture for ritual in a ward setting. Rituals existed in the working day of the nurses studied. Rituals were not an indication that ritualised behaviour is harmful to individualised patient care. Other themes which explored – social structures, authority, economic system, communication and socialisation.
Seymour, J. E. (2000) Negotiating natural death in intensive care. <i>Journal of Social Science and Medicine</i> , 51:1241-1252.f	Ethnography Observational case study design UK study	14 case studies & interviews with nurses & relatives (conducted in 2 ICU's in UK)	The establishment of technical dying informed by results of investigations and monitoring equipment, and bodily dying informed by clinical experience, The alignment of the trajectories of technical and bodily dying to ensure that the events of non-treatment have no perceived causative link to death, The balancing of medical action with non-action, allowing a diffusion of responsibility for death to the patient's body, The incorporation of patient's companions and nursing staff into the decision making process.
Kirchhff, K. T., Spuhler, V., Walker, L., Cole, V. and Clemmer, T. (2000) Intensive care nurses' experiences with end-of-life care. <i>American Journal of Critical Care</i> , 9(1):26-36-42.	Qualitative descriptive study American study	focus groups and clinicians from 4 ICU's in 2 hospitals	good end-of-life care in the ICU was described as ensuring the patient was pain free and the patient's comfort and dignity was ensured. Changes in the physical environment, education about end-of-life care, staff support, and better communication would improve care of dying patients and their families.

Miller, P. A., Forbes, S. and Boyle, D. K. (2001) End-of-Life Care in the Intensive Care Unit: A Challenge for Nurses. <i>American Journal of Critical Care</i> , 10(4): 230-237.	Literature review American study	Focus on exploration of contemporary cultural issues that influence the delivery of ICU care; the reason for limited involvement of nurses in end-of-life decision making and planning; and recommendations for future practice.	Biomedical knowledge as the dominant conceptual framework The technological imperative Incompatibility of lay and medical knowledge Ambivalence about end-of-life goals limited involvement of intensive care nurses in decision making process Shared decision making in the ICU is paramount.
Puntillo, K. Benner, P., Drought, T., Drew, B., Stotts, N., Stannard, D., Rushton, C., Scanlon, C., and White, C. (2001) End-of-life issues in intensive care units: A national random survey of nurses' knowledge and beliefs. <i>American Journal of Critical Care</i> , 10(4): 216-229.	Quantitative Survey American study	Survey of 3,000 members of AACCN 30% return rate (906 responded) Questionnaire with scenarios – 99% agreed with withdrawal of treatment and pain management. Staff debriefing rarely occurred (38%).	Intensive care nurses strongly support good pain management for dying patients and withdrawal of treatment therapies to allow unavoidable death. Wider professional and public dialogue on end-of-life care in the ICU is warranted.
Seymour, J. E. (2001) <i>Critical Moments – Death and Dying in Intensive Care</i> . Open University Press: Buckingham.	Qualitative Ethnography Case studies,	Comparison between UK & USA ICU's (Kirchhoff <i>et al</i>) Purposive	'Bodily & technical dying' Emotional labour of nursing, 'good death'

	interviews UK study	Healthcare staff Relatives/companions Consent (continuous) - 14 case studies & interviews with nurses & relatives (conducted in 2 ICU's in UK) Three themes – related to traditional nursing issues Social constructionist perspective Negotiated order Construction of 'good death' Cure-care continuum	Withdrawal of treatment Data collected - wealth of real, 'lived', in-depth data Authenticity, originality, credibility Continuity of care across healthcare system was a problem Need for enhancing teamwork & staff support Involvement, participation & support of relatives & staff during decision-making process and the dying trajectory
Philpin, S. M ((2002) Rituals and nursing: a critical commentary. <i>Journal of Advanced Nursing</i> , 38(2): 144-151.	critical commentary Uk study	The meaning of the term 'ritual' is discussed through the medium of a literature search	two broad themes emerged – the definition of ritual is complex and the purposes served by ritual. This paper concludes with the recommendation that the rituals nurses use in the performance of their care are worthy of research as a rich source of insight into the meaning and purpose of nursing actions.
Sprung <i>et al.</i> (2003) End-of-life practices in European intensive	Prospective, observational	Prospectively defined end-of-life practices in 37 ICU's	Limiting of life-sustaining treatment in European ICU's is common and associated

care units: the Ethicus Study. <i>Journal of the American Medical Association</i> , 290: 790-797.	study of European ICU's European study led by Sprung (Israel)	in 17 European countries 31,417 patients 38% of patients had withdrawal of treatment	with patient age, diagnoses, ICU stay, and geographic and religious factors. Shortening of the dying process is rare, but clarity needed between withdrawing therapies and shortening the dying process. Authors suggest further research with regard to perspectives of physicians, nurses, patients and families regarding the dying process in ICU in different countries and different cultures.
Cook, D., Rocker, G., Sjøkvist, P., Dodek, P., Griffith, L., Freitag, A., Varon, J., Bradley, C., Levy, M., Finfer, S., Hamielec, C., McMullin, J., Weaver, B., Walter, S., and Guyatt, G. (2003) Withdrawal of mechanical ventilation in anticipation of death in the intensive care unit. <i>The New England Journal of Medicine</i> , 349: 1123-1132.	Quantitative study using SPSS American study	851 patients who were receiving mechanical ventilation in 15 ICU's	19.5 % had withdrawal of mechanical ventilation and the need for inotropes or vasopressors was associated with withdrawal of the ventilator. Determinants of the withdrawal of ventilation in critically ill patients were the physician's perception that the patient preferred not to use life support, the physician's predictions of a low likelihood of survival in the ICU, a high likelihood of poor cognitive function and the use of inotropes or vasopressors.
Pattison, N. (2004) Integration of critical care and palliative care at end of life. <i>British Journal of Nursing</i> , 13(3):132-139.	clinical review UK study		The transition from cure to comfort does not emphasise a dichotomy between palliative care and critical care but should focus on the best possible end-of-life care.
Halcomb, E., Daly, J. Jackson, D. and Davidson, P. (2004) An insight into Australian nurses' experience of	Qualitative, Van Manen's phenomenology	Australian study, 3 different general ICU's, study explored the lived experiences of the	5 themes emerged from study – comfort and care, tension and conflict, beneficence, nurse/family relationships, invisibility of grief and suffering.

withdrawal/withholding of treatment in the ICU. <i>Intensive and Critical Care Nursing</i> , 20:214- 222.	Australian study	participants (nurses)	
Wunsch, H., Harrison, D. A., Harvey, S and Rowan, K. (2005) End-of-life decisions: a cohort of the withdrawal of treatment of all active treatment in intensive care units in the United Kingdom. <i>Intensive Care Medicine</i> , 31(6): 823-831.	Quantitative study UK study	Cohort study in 127 adult ICU's in England, Wales and Northern Ireland. 118,199 adult admissions to ICU's	Withdrawal of treatment for 9.9% of cohort 31% of cohort deaths occurred after the decision to withdraw treatment was made Median time to death after withdrawal of treatment was 2 to.4 hours, with 8% surviving more than 24 hours Withdrawal of treatment is widespread in ICU's in the UK with considerable variation in different ICU's Suggestions for improved guidelines to facilitate uniform decision making.
Bergstrand, R. L., and Kirchhoff, K. T. (2005) Providing end-of-life care to patients: Critical care nurses' perceived obstacles and supportive behaviours. <i>American Journal of Critical Care</i> , 14(5): 395-403.	Experimental, post-test, control-group designed survey American study	Questionnaire 1500 members of American Association of Critical Care Nurses – randomly selected from 68,000 members. Response rate = 61.3%	Biggest obstacles to appropriate end-of-life care in ICU is the behaviour of patient's families that remove nurses from caring for patients, behaviours that prolong patients' suffering or cause pain, and physicians' disagreement about the plan of care.
Badger, J. (2005) Factors that enable or complicate end-of-life transitions in critical care. <i>American Journal of Critical Care</i> , 14(6):513-520.	Descriptive qualitative research design American study	25 ICU nurses in 18-bed ICU Observation and focus group interviews	Transition between cure to comfort was unclear Distressing situations experienced by staff included dealing with younger patients with an acute life-threatening illness and performing futile care on elderly patients. End-of-life transitions were difficult when patients' families had conflicts or were indecisive about terminal treatment and when physicians kept offering options that were unlikely to change patients' prognosis. The most important factor enabling nurses to move from cure to comfort care was

			developing a consensus about the treatment.
Costella, J. (2006) Dying well: nurses' experiences of 'good and bad' deaths in hospital. <i>Journal of Issues and Innovation in Nursing Practice</i> , 594-601.	Qualitative descriptive UK study	29 registered nurses in UK hospital	Management of death in hospital is major source of conflict for nurses. Good and bad death experiences depending on the order of the ward. Good and bad deaths focused less on patient's needs and the dying process and more on the death event and nurses' abilities to manage organisational demands.
Beckstrand, R. L., Callister, L. C. & Kirchhoff, K. T. (2006) Providing a 'Good Death': Critical Care Nurses' Suggestions for Improving End-of-Life Care. <i>American Journal of Critical Care</i> , 15(1): 38-45.	Qualitative enquiry Survey method 72 - item questionnaire on perceptions of EOL care Viewpoints of & the implementation of suggestions by experienced ICU nurses may increase the quality of EOL care thus facilitating a 'good death' for critically ill patients American study	1,409 critical care nurses (AACCN) 861 questionnaires returned (61%) Open-ended questionnaire 93% female Mean age = 44.6 yrs 53% - staff nurses 36% - charge nurses 10%- nurse specialists Settings - trauma, CCU, neurosurgery, medical & surgical ICU's 70% respondents had cared for >30 dying patients with mean ICU work experience = 16 years	Staffing patterns & shortage of nurses, ethos of critical care, patient transfer out of ICU Lack of time to providing a 'good death', lack of communication between physicians & families, unrealistic re: prognosis Physicians view patient's death perceived as a failure Suggestions - Creating conducive milieu for dying e.g. being present, managing pain & discomfort, respecting patient's wishes re: EOL care, earlier cessation of Rx, communication effectively as healthcare team Educational initiatives - for both medical & nursing staff re: dying & death
Robichaux, C. M., and Clark, A. P. (2006) Practice of expert	Qualitative narrative analysis	Interviews with 21 critical care nurses from 7 ICU's	Narratives of protecting or advocating on behalf of the patient concerned preventing further technological intrusion and thus permitted a dignified death.

critical care nurses in situations of prognostic conflict at the end of life. <i>American Journal of Critical Care</i> , 15(5): 480-489.	American study	Research evidence suggests critical care nurses assume a limited role in end-of-life decision making and care planning.	<p>Presenting a realistic picture involved helping families reframe the potential for recovery.</p> <p>Inability to affect a patient's situation was expressed in narratives of frustration and resignation.</p> <p>The expert nurses demonstrated the ability and willingness to actively protect and advocate for their vulnerable patients even in situations in which the nurses' actions did not influence the outcomes.</p>
Hov, R., Hedelin, B. and Athlin, E. (2006) Being an intensive care nurse related to questions of withholding or withdrawing curative treatment. <i>Journal of Clinical Nursing</i> . 203-211.	Qualitative, interpretive phenomenology. Norwegian study	Focus group interviews 14 female intensive care nurses	<p>Loneliness in responsibility</p> <p>Alternation between optimism and pessimism</p> <p>Uncertainty</p> <p>A constant shadow and professional pride despite little formal influence (a critical interpreter and a dedicated helper)</p> <p>The findings underpin the important role of intensive care nurses in providing care and treatment to patients related to questions of withholding and withdrawing curative treatment.</p>
Philpin, S. (2006) Managing ambiguity and danger in an intensive therapy unit: ritual practices and sequestration. <i>Journal of Nursing Inquiry</i> , 14(1): 51-59.	Ethnography UK study	Participant observation and interviews with 15 nurses	<p>Draws on anthropological concepts of liminality, pollution, anomaly and breaching of boundaries</p> <p>The paper identifies ambiguities inherent in ICU patients' condition and explores the ways in which these anomalies are managed through sequestration and other ritual and symbolic practices.</p>
Pattison, N. (2006) A critical discourse analysis of provision	Discourse analysis design	Article highlights certain practical and professional	Key documents give little clear guidance about how to provide EOL care in critical care.

of end-of-life care in key UK critical care documents. <i>Critical Care Nursing</i> , 11(4): 198-208.	UK study	difficulties in providing end-of-life care for patients in ICU's and explores discourses arising from guidelines for critical care services	Discourses include the power dynamic in critical care between professions, families and patients, and how this impacts on the provision of EOL care. Difficulties encountered include dilemmas at discharge and paternalism in decision making. The technological milieu can act as a barrier to good EOL care and critical care nurses are at risk of assuming the dominant medical model of care. However, these nurses are in a prime position to ensure that decision making is an inclusive process, patient needs are paramount, the practical aspects of withdrawal of treatment lead to a smooth transition in goals of care and that comfort measures are implemented.
McMillen, R. E. (2007) End of life decisions: Nurses perceptions, feelings and experiences. <i>Intensive and Critical Care Nursing</i> , 24: 251-259.	Grounded theory design UK study	Sample of 8 intensive care nurses with semi-structured interviews	The nurse's role – experience counts, not really a nurse's decision, planting the seed, supporting the family and being a patient advocate Perceptions of the withdrawal of treatment – getting the timing right and emotional labour.
Hov, R., Hedelin, B. and Athlin, E. (2007) Good nursing care to ICU patients on the edge of life. <i>Intensive Care and Critical Care Nursing</i> , 23:331-341.	Qualitative, grounded theory Norwegian study	nurses' experiences, 14 female nurses, Norway	Good nursing care depended several conditions – continuity, knowledge, competence, co-operation and clear goals for end-of-life care.
Morgan, J. (2008) End-of-life care in UK critical care units – a literature review. <i>British Association of Critical Care Nurses</i> , 13(3):152-161.	literature review UK study		The literature reveals a paradigm shift from critical to palliative care in the ICU during end-of-life. Quality EOL care involves the assessment, ongoing organisational and educational support at local and national levels. Critical care nurses have an extraordinary opportunity to make a difference to the dying patient and their family and their acceptance of death.
Shorter, M. and Stayt, L. C.	Heideggerian	Interviews with 8 critical	The death of the patient was perceived less traumatic if the participant thought it

(2009) Critical care nurses' experiences of grief in an adult intensive care unit. <i>Journal of Advanced Nursing</i> , 159-167.	phenomenological approach UK study	care nurses	<p>was a good death, expected and good nursing care was delivered.</p> <p>Meaningful engagement was important with the patient and family</p> <p>Participants exhibited signs of normalising death and described how they disassociated themselves emotionally from dying patients</p> <p>Informal supportive conversations with colleagues were described as a means of coping.</p>
Fridh, I., Forsberg, A. and Bergbom, I. (2009) Doing one's utmost: Nurses' descriptions of caring for dying patients in an intensive care environment. <i>Intensive and Critical care Nursing</i> , 25:233-241.	Qualitative descriptive approach Swedish study	interviews with 9 experienced ICU nurses	Focus was on nurses ensuring dignified dying process and support relatives in a calm manner to give them an enduring memory of their loved one's death.
Mohammed, S. and Peter, E. (2009) Rituals, death and the moral practice of medical futility. <i>Journal of Nursing Ethics</i> , 16(3):292-302.	literature review Canadian study		The authors examined CPR and life-sustaining measures as moral practices and found that futile interventions offered ritualistic benefit to patients, families and healthcare providers and also helped the dying process. It offers a new perspective on the ethical debate concerning medical futility and uses Walker's expressive-collaborative model of morality to examine how certain critical care interventions that are considered futile actually have broader social functions surrounding dying and death.
Latour, J., Fulbrook, P and Albarran, J. W. (2009) EfCCNa survey: European intensive care nurses' attitudes and beliefs towards end-of-life care. <i>Nursing in Critical Care</i> , 14(3): 110-121.	Survey method with structured attitudinal questionnaire European study	<p>419 delegates at EfCCNa conference (worldwide nurse representation-clinical, research & education)</p> <p>164 questionnaires were completed</p> <p>Questionnaire composed of</p>	<p>European IC nurses' involvement in EOL care decisions & the extent to which their practice is based on shared beliefs, experiences & attitudes</p> <p>Withholding Rx</p> <p>Withdrawing Rx (practices & procedures)</p> <p>EOL decision</p> <p>EOL care</p>

		<p>45 items</p> <p>Available in 3 languages (Dutch, Italian & English)</p> <p>Response rate 39%</p> <p>Questionnaire themes:</p> <ul style="list-style-type: none"> - NB of religious views when making decision to WOT <p>(Patient views – 40%, Family views – 9%, Nurses -1% Medical -1%)</p> <ul style="list-style-type: none"> - NB of expected outcome assessment by medical/nursing team - Nurses' experiences & involvement in EOL decisions - Nurses' beliefs of EOL practice 	<p>Shared outlook re: EOL - differences may be due to culture, religious views & educational preparedness of staff,</p>
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Stayt, L. C. (2009) Death, empathy and self-preservation: the emotional labour of caring for families of the critically ill in adult intensive care. <i>Journal of Clinical Nursing</i> , 18: 1267-1275.	Heideggarian phenomenological design UK study	12 intensive care nurses Interviews	Emotional work forms an important part of the critical care nurse's role. The significance of death, breaking bad news, and interpersonal relationships are sources of emotional stress for the critical care nurse caring for the family of the critically ill. Potentially, unless supported and managed, emotional labour may lead to occupational stress and ultimately burnout.
Waraporn, K. (2009) Promoting peaceful death in the intensive care unit in Thailand. <i>International Nursing Review</i> , 56(1):116-122.	Qualitative, phenomenological study Thai study	10 ICU nurses in Thailand, interviews	Themes – peaceful death – understanding the other through valuing experience and enhancing relationships with others by recognising time is short and is a priority.
Ranse, K.; Yates, P. and Coyer, F. (2010) End-of-Life care in the intensive care setting: A descriptive exploratory qualitative study of nurses' beliefs and practices. <i>Australian Journal of Critical Care</i> , 25:4-12.	Qualitative, descriptive study Australian study	5 intensive care nurses, semi-structured interviews	Three themes emerged – beliefs and end-of-life; end-of-life in the ICU; and facilitating end-of-life care. Care of the family was at the core of nurses' end-of-life care work and nurses played a pivotal role in supporting the patient and family to have positive and meaningful experiences at the end-of-life.
Kongsuwan, W. and Locsin, R. C. (2010) Thai nurses' experiences of caring for persons with life-sustaining technologies in intensive care settings: A phenomenological study. <i>Intensive and Critical Care Nursing</i> , 27: 102-110.	Heideggarian phenomenological design Thai study	8 intensive care nurses - interviews	Themes of Corporeality, relationality, temporality and spatiality. The experience of caring for is described as valuing competency to care despite differing insecurities in the use of technology. Influenced by relationships and compassion, the risk that technology prevented an appreciation of persons as wholes is embodied in the encouraging collaboration of fostering time to care regardless of being in a restricted space surrounded by technology.
Festic <i>et al.</i> (2011) Perspectives of physicians and nurses regarding end-of-life care in the intensive care unit. <i>Journal of</i>	Survey method with structured attitudinal	Questionnaire themes: NB of religious views when	91.8% respondents were actively involved in EOL care 73.4% respondents actively involved in decision-making

<p><i>Intensive Care Medicine.</i> Published online before print January 21, 2011, doi.10.1177/0885066610393465.</p>	<p>questionnaire</p>	<p>making decision to WOT (Patient views – 40%, Family views – 9%, Nurses -1% Medical -1%) NB of expected outcome assessment by medical/nursing team Nurses' experiences & involvement in EOL decisions Nurses' beliefs of EOL practice Withholding &Withdrawal of Rx (practices & procedures) EOL decision EOL care Shared outlook re: EOL with differences due to culture, religious views & educational preparedness of staff</p>	<p>In WOT - 65% respondents would decrease O2 flow, Pt. transfer - 91% disagree 98% respondents would provide continuous pain relief 91% respondents would endorse fluids Generally, the views & experiences of EOL care were similar, with the exception of the provision of nutrition & use of sedation Increased autonomy re: decision-making for UK nurses</p>
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<p>Efstathiou, N. and Clifford, C. (2011) The critical care nurse's role in End-of-Life care: issues and challenges.</p> <p><i>British Association of Critical Care Nurses: Nursing in Critical Care</i>. 16(3): 116-123.</p>	Literature Review	<p>Review of the literature with regard to issues & challenges critical care nurses face when looking after patients needing end-of-life care in the ICU</p>	<p>Communication skills needed for delivering quality compassionate care to dying patients & their families</p> <p>Multi-disciplinary team communication</p> <p>Patient & family-centred decision –making</p> <p>Continuity of care</p> <p>Symptom management & comfort care</p> <p>Spiritual support</p> <p>Emotional & organisational support</p>
<p>Cypress, B. (2011) The lived ICU experience of nurses, patients and family members: a phenomenological study with Merleau-Pontian perspective. <i>Intensive and Critical Care Nursing</i>, 1-8.</p>	<p>Qualitative, phenomenological study</p> <p>USA</p>	<p>nurses, patients and family members – interviews</p> <p>USA</p>	<p>Themes – corporeality, temporality, spatiality and relationality. Focus on family-centred care and family involvement in all aspects of patient care in ICU</p>
<p>Vouzavali <i>et al</i>, (2011) 'The patient is my space': hermeneutic investigation of the nurse-patient relationship in critical care. <i>Nursing in Critical Care</i>, 16(3): 140-151.</p>	<p>Qualitative</p> <p>Heideggerian Phenomenology study</p> <p>Interviews</p> <p>Greek study</p>	<p>12 ICU nurses</p> <p>Core themes: -</p> <p>Syncytium</p> <p>Emotive aspects of nurse/patient relationship</p> <p>Compassion</p>	<p>Critical care nurses experience deep relationship with patients mediated by continuous contact with patient's bodies. They experience feelings of love, empathy and care – this affects how nurses perceive their role & their world</p> <p>Core theme – syncytium, authentic care & 'being- in- the- world'</p> <p>Temporality, spatiality & meanings attributed to nurses role in dying & death in the ICU</p> <p>Implications for critical care nurses educational preparation & psychological</p>

		<p>Gratifying & wearisome relationship</p> <p>Spatiality & temporality</p> <p>Patient's body & gaze</p> <p>Empathy</p> <p>Focus on critical care nurse/patient relationship</p>	<p>support</p> <p><i>'You are there all the time. You must be with the patient all the time... patient' are constantly face to face with the nurse'</i></p> <p><i>'...if it is threatened, that piece, that particular piece, of the body, is what you need to save...'</i></p>
<p>Coombs, M. A.; Addington-Hall, J. and Long-Sutehall, T. (2011) Challenges in transition from intervention to end of life care in intensive care: A qualitative study. <i>International Journal of Nursing Studies</i>, 49: 519-527.</p>	<p>Qualitative study</p> <p>UK study</p>	<p>semi-structured interviews with 13 medical staff & 13 nurses in 2 ICU's</p>	<p>Three themes emerged at end of life – admission with hope of recovery; transition from intervention to end of life; controlled death.</p> <p>Findings suggest in ICU there is a need to focus on the transition from curative intervention to end of life, rather than end of life itself so that timely and effective decision making underpins the care of the 20% of patients who undergo withdrawal of treatment.</p>
<p>Blows, E., Bird, L., Seymour, J. and Cox, K. (2012) Liminality as a framework for understanding the experience of cancer survivorship: a literature review. <i>Journal of Advanced Nursing</i>, 1-10.</p>	<p>Narrative review of literature</p> <p>UK study</p>	<p>rites of passage model, liminality and transition – literature review, 10 studies included for review</p>	<p>Rites of passage model, liminality and transition in cancer patients. Further research exploring the personal and social implications of living a liminal life, at all stages of the cancer trajectory is warranted.</p>

Appendix D: Flyer



To all relatives/family/significant others of patients in the ICU

Please note there will be a researcher in the ICU undertaking a study which will involve observing intensive care nurses conducting their nursing activities. If you would prefer the researcher not to be present please inform the ICU Matron or the researcher.

The researcher will be identified with a name badge and is Jenni Templeman, a Professional Doctorate student in Health and Social Care.

If you require further information or have any questions, please speak to Jenni Templeman or Ellis Clarke, the Intensive Care Matron.



To All ICU Staff

Please note there will be a researcher in the ICU undertaking a study which will involve observing intensive care nurses conducting their nursing activities.

The researcher will be identified with a name badge and is Jenni Templeman, a Professional Doctorate student in Health and Social Care.

If you require further information or have any questions, please speak to Jenni Templeman or Ellis Clarke, the Intensive Care Matron.

Appendix E: Invitation letter



Appendix 5

Version 1 (03/06/11)

Title of Research Project: 'An ethnographic study of critical care nurses' experiences following withdrawal of life-sustaining treatment to patients in the adult intensive care unit'.

Date:

Dear

You are invited to participate in a research study conducted by myself, Jenni Templeman, a Professional Doctorate student in Health and Social Care at the University of Salford.

The research enquiry will explore and offer insight into intensive care nurse practitioners' experiences within the intensive care culture following withdrawal of life-sustaining treatment (e.g. advanced respiratory, cardiovascular, hepatic, neurological and renal support) to level 3 patients and how they make sense of dying and death within the culture of this clinical environment. The focus will be on intensive care nurse practitioners' experiences, activities and coping strategies relevant to withdrawal of life-sustaining treatment through the exploratory lens of ethnography.

The research methods which will be used for the study include non-participant observation and semi-structured interviews. The interview discussion will be about your experiences and will last one hour. These interviews will span over time and will fit in with you and your wishes.

With your permission I hope to tape-record the interview discussion so that I have an accurate and precise record of the discussion. I will be the only person who knows whom has been involved in the study and will ensure that your name will not be linked with any data that appears in any reporting of the research. In other words, privacy and concealment of your name and details will be secured and maintained. Your decision to participate in the research is yours and should you agree and then later change your mind that is your right and I will respect your wishes. If you wish to participate I will contact you to arrange an agreed date and suitable time for the interview.

The tape recordings of the interview discussion will be coded and stored separately from any list that links your name or details. They will be stored in a locked filing cabinet in my office at the University of Chester where I work. The tapes will be destroyed after the study has been completed and you can have your own copy.

I would be happy to discuss the study with you at any time and thank you for your time and support.

Kind regards

Jenni Templeman

(W) 01925 534226

Email: j.templeman@chester.ac.uk

Appendix F: Participant information sheet



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Version 2 (05/07/11)

Participant Information Sheet

'An ethnographic study of critical care nurse practitioners' experiences following life-sustaining treatment to patients in the adult intensive care unit'.

You are invited to participate in a research study. Before you decide, it is important for you to understand why the research is being conducted and what it will involve. Please take time to read the following information carefully and discuss it with your colleagues if you wish. Please ask the researcher if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to participate.

Thank you for reading this.

- **What is the purpose of the study?**

Intensive care practitioners are primarily concerned with the salient issues of human dignity, effective communication and utilising advanced assessment skills to provide optimal, high quality treatment options, whilst remaining respectful of each patient's individual, holistic needs and bodily integrity (Rubenfeld & Crawford, 2001). The purpose of this study is to explore and offer insight into nurses' experiences within the intensive care unit and culture following withdrawal of life-sustaining treatment to patients and how nurses make sense of dying and death within clinical practice.

- **Why have I been chosen to participate?**

The researcher is interested in Band 5, 6, 7 and 8 intensive care nurses' experiences following withdrawal of treatment. You will be a representative of one of these nursing Bands.

- **Do I have to participate?**

No – you are not obliged to participate in the study. You do not have to give any reason or explanation for your decision to decline participation.

- **What will be expected of me if I participate?**

You will be asked if you are willing to be observed following the withdrawal of life-sustaining treatment and during the interview you will be presented with two scenarios for your comment and discussion. The interview will be conducted over a period of one hour in a room separate from the intensive care unit within the intensive care complex. The interviews will be conducted in off duty time and the responses will be tape-recorded. The sample is purposive and the participants within the study will include Band 5, 6 and 7 nurses within the intensive care setting. The sample size will comprise ten to fifteen participants for the semi-structured interviews (preferably five participants from each nursing Band in order to obtain a representation of the intensive care nursing population). The researcher is aware of the processes for the management of stress in place within the intensive care unit and they will be followed during the conduct of the study.

During non-participant observation, only intensive care nurses will be observed. The participants for non-participant observation may not be the same participants selected for the semi-structured interviews.

What are possible disadvantages and risks for participating?

There are no likely disadvantages or anticipated risks involved in your participation. In the event of you becoming anxious or distressed during the interview due to the sensitive topic of dying and death, the interview will be stopped immediately and a debriefing session will be conducted by the researcher if necessary.

- **What are the benefits of participating?**

You will be contributing to the existing body of intensive care research knowledge relevant to the topic, as this study is about **your experiences** following withdrawal of life-sustaining treatment.

The research will also highlight issues of clinical interest relevant to nurses involved with the care of the dying patient in the intensive care unit following withdrawal of life-sustaining treatment.

- **Will my participation in this study be confidential?**

Yes. Interviews will be recorded, coded and transcribed verbatim with your consent. Your responses during the interview may be read by you and checked if you so wish. Your participation during observation will also remain confidential. If any participant should waiver consent during observation, then the participant's observed actions will be omitted from the field notes and observation data. The research study will be available for you to read once completed. The consent forms which you sign for both observation and the interview will be kept in a locked, secure facility in the care of the researcher and will be destroyed at the end of the research project. All data collected from the observation and interviews will be processed on a password protected laptop, which only the researcher will have access to. All data collected during the study will be stored for 5 years and then shredded and disposed of in the university's confidential waste system.

- **What will happen to the findings of the research study once completed?**

The information gathered will be analysed and presented in the format of a thesis being undertaken for a Professional Doctorate in Health and Social Care and will disseminated through journal publication and conference presentation. Your quotes from the interviews will remain anonymous, be coded and transcribed with your consent. Confidentiality will be

maintained throughout the study. The findings will be reported back to the participants and the unit staff.

- **Who has reviewed the study?**

All research in the NHS is looked at by an independent party called a Research Ethics Committee in order to protect your safety, rights, well-being and dignity.

- **Who is organising and funding the research?** The researcher (Jenni Templeman).
- **Who may I contact for further information?** Jenni Templeman (researcher) or Ellis Clarke (ICU Matron).

Email: j.s.templeman@edu.salford.ac.uk; Tel (W) 01925 534226

Email: ellis.clarke@whh.nhs.uk; Tel: (W) 01925 662508

Thank you for your interest in this research project

Appendix G: Consent forms (interview and observation)



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Version 2 (05/07/11)

Consent Form for Interview

Title of Research Project: 'An ethnographic study of critical care nurses' experiences following withdrawal of life-sustaining treatment to patients in the adult intensive care unit'.

Name of Researcher: Jenni Templeman

Please initial box

1. I confirm that I have read and understand the information sheet dated (version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason or legal rights being affected. ☐
3. I understand that relevant sections of any data collected during the study, may be looked at by the researcher's supervisor from University of Salford , where it is relevant to my taking part in this research. I give my permission for these individuals to have access to the data. ☐
4. I agree to take part in the above mentioned research study.
5. I agree for the interview to be audio taped.
6. I agree for anonymised direct quotations to be used for publication.

Name of Participant

Date

Signature

Name of Researcher

Date

Signature

(When completed: 1 copy for participant; 1 copy for researcher)



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Consent Form for Observation

Title of Research Project: 'An ethnographic study of critical care nurse practitioners' experiences following withdrawal of life-sustaining treatment to patients in the adult intensive care unit'.

Name of Researcher: Jenni Templeman

Please initial box

1. I confirm that I have read and understand the information sheet dated (version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason or legal rights being affected.
3. I understand that relevant sections of any data collected during the study, may be looked at by the researcher's supervisor from the University of Salford, where it is relevant to my taking part in this research. I give permission for these individuals to have access to the data.
4. I agree to take part in the above study.
5. I agree to be observed in my role as an ICU practitioner
6. I agree for anonymised direct quotations to be used for publication.

Name of Participant

Date

Signature

Name of Researcher

Date

Signature

(When completed: 1 copy for participant; 1 copy for researcher)

Appendix H: Scenarios/vignettes used in interviews

Scenario/Vignette 1

A 49 year old semi-conscious man who received a liver transplant one year ago now has sepsis with multiple organ failure, and all efforts at treating the infection have been unsuccessful. There are no medical therapies left that could alter an almost certain fatal outcome to this illness. The intensive care team and the patient's family decide that mechanical ventilation should be withdrawn. At the family's request, all therapies are stopped except for intravenous Morphine and Midazolam in small doses sufficient to keep the patient pain free and comfortable. The decision is taken to extubate the patient.....

1. What do you think is happening in this scenario?
2. What makes you think this?
3. Have you experienced a similar situation?
 - 3 a) If Yes, can you tell me about it?
4. How did/would you feel in this situation?
5. In your experience, do you stay with the family of the patient throughout WOT?
6. As a nurse, are you included in the decision making process with regard to WOT?
7. Would you feel comfortable with a patient who is extubated during WOT?

Scenario/Vignette 2

A 76 year old woman with diabetes mellitus and ischaemic heart disease was admitted to the ICU two months ago. Her condition has steadily deteriorated and she has established sepsis not responding to antibiotics. She now has gangrene in both legs and hands. The patient is not a candidate for surgery. She is being treated with multiple vasopressor therapies to maintain her cardiovascular status and she is mechanically ventilated on 100% oxygen. Her family insist on continuing with all treatment despite being told that her prognosis is poor and that further treatment is futile.....

1. Would you like to discuss this scenario?
2. How do you feel about her family insisting that all treatment should continue despite her poor prognosis?
3. Have you experienced a similar situation?
4. How would you feel in this situation?
5. Can you tell about it?
6. Do you think WOT could be viewed as a failure?
7. From my observation, I have noticed that the patient is washed prior to WOT?
8. What equipment would you normally withdraw first during WOT?
9. In your experience, what was the shortest time from WOT to death?
10. And the longest time?
11. I notice the curtain is drawn around the bed once the decision to withdraw treatment has been made. Why do you think this is so?

Would you like to discuss a situation where you have withdrawn treatment?

1. Was it a young or elderly patient?
2. How did you feel in your role as a nurse during the withdrawal of treatment phase?
3. When did you break the news to the patient's family after the decision to withdraw treatment was made?
4. How did you feel in this situation?
5. Did you stay with the patient and family during WOT?
6. Were you included in the decision making process?
7. Did you discuss with the family after breaking the news if they wanted the ECG monitor on or off? Did you have time for a debriefing session following WOT?
8. How many WOT's have you conducted in your ICU experience?

Participant:

Date:

Band:

Gender:

Nationality:

Religion:

ICU experience:

Other experience & years:

Appendix I: An example of Ricoeur's analytical framework for the data analysis of interviews

Participant K (aka Efa)

Band 5, Female, British, 16 years ICU experience

Vignette 1 (<i>transcribed interview with participant's response</i>)	Explanation (what the text is actually saying)	Naïve understanding [Interpretation] – (what I think the text means)	Appropriation – deeper understanding (what I think it means to wider knowledge and clinical practice)	Themes and sub-themes
<p>A 49 year old semi-conscious man who received a liver transplant one year ago now has sepsis with multiple organ failure, and all efforts at treating the infection have been unsuccessful. There are no medical therapies left that could alter an almost certain fatal outcome to this illness. The intensive care team and the patient's family decide that mechanical ventilation should be withdrawn. At the family's request, all therapies are stopped except for intravenous Morphine and Midazolam in small doses sufficient to keep the patient pain free and comfortable. The decision is taken to extubate the patient.....</p> <p>Q 1.1) Interviewer: What do you think is happening in this scenario? <i>Efa: Well this patient is in multiple organ failure and has sepsis which</i></p>	<p>Nurse discusses her interpretation of the</p>	<p>Nurse assesses the situation and rationalises the decision</p>	<p>Nurse rationalises the withdrawal decision based on</p>	<p>Clinical knowledge; nurse's knowledge</p>

<p><i>has a poor prognosis...added to this he appears to be in rejection or failure of his transplanted liver which is also not good news. It mentions there are no medical therapies left to offer so the situation looks bleak for him. Withdrawal of treatment would be based on futility...but he is young...it sounds as if he has been given everything that is available but the outcome is poor. I get upset when it happens in a young patient, but there is only so much we can do. He is however being kept pain free and sedated and his family are in agreement with the decision. The decision to extubate him has probably been influenced by the consultant's opinion. It is hard to withdraw on young patients...to accept that we have lost the battle to save a patient...</i></p>	<p>scenario and describes the MOF and possible transplant rejection and her feelings of being upset as this is a young patient. She goes on to say that due to the poor outcome unfortunately there are no further options available to the patient – she then mentions that the patient should be kept sedated and pain free and the family are in agreement with the decision to withdraw treatment.</p> <p>She acknowledges that the consultant has decided to extubate the patient. Goes on to again say it is hard to withdraw on young patients as it feels as if the nurse has lost the battle to save a life.</p>	<p>to withdraw but feels upset when this happens in a young patient.</p> <p>As long as the patient is kept pain free and sedated and the family agree with the withdrawal of treatment (WoT) decision, the nurse appears satisfied that there is not much more to offer this patient in the scenario.</p> <p>She readily accepts consultant's decision to extubate. Stresses it is difficult to withdraw in young patients and also difficult to accept that she has lost the battle to save the patient's life.</p>	<p>her clinical knowledge and experience but feels upset and sad that it is a young patient.</p> <p>Nurse feels content that it is right decision if the patient is kept pain free and sedated and the family are in agreement with the WOT decision.</p> <p>Consultant's prerogative to extubate and remove airway.</p> <p>Difficult to withdraw in young patient. She feels that it is difficult to accept that the battle to save the patient's life has been lost.</p>	<p>and experience; intuition</p> <p>Sadness - withdrawing from young patient</p> <p>Terminal extubation</p> <p>Unable to save patient – may be viewed as a failure</p> <p>loss of control</p> <p>no longer a challenge</p> <p>If unable to cure then aim for dignified death (good death)</p>
<p>Q 1.2) Interviewer: What makes you think this?</p> <p><i>Efa: Purely from my experience and other cases I have nursed who have been similar.</i></p>	<p>previous nursing experience of this type of scenario.</p>	<p>previous nursing experience of this type of scenario.</p>	<p>past experience in the ICU</p>	<p>nurse's knowledge and experience</p>
<p>Q 1.3) Interviewer: Have you experienced a similar situation?</p> <p><i>Efa: Often, in fact very often in my experience.</i></p>	<p>She has experienced similar situations very often.</p>	<p>this suggests that withdrawal of treatment (WOT) occurs often</p> <p>.</p>	<p>very often so nurse has experience in withdrawing treatment</p>	<p>nurse's knowledge and experience</p>

<p>Q 1.4) Interviewer: In your experience, do you stay with the family of the patient throughout WOT?</p> <p><i>Efa: Yes, I do because I believe this is an important part of the final care of the patient and their family.</i></p>	<p>Stays with family during WOT as she feels this is an important part of the final care of the patient and family.</p>	<p>Stays with family during WOT as she feels this is an important part of the final care of the patient and to support family.</p>	<p>belief in caring for patient during WOT and also to support the patient's family during this fraught time</p>	<p>Patient care</p> <p>family support</p> <p>nursing roles</p>
<p>Q 1.5) Interviewer: As a nurse are you included in the decision-making process with regard to WOT?</p> <p><i>Efa: Yes, we as nurses were always included in the decision but it was the consultant in charge of the patient who made the ultimate decision according to the legal requirements and responsibility given to his role and status...the more experience the nurse has the more we are involved in the decision making process...</i></p>	<p>Efa feels she is always included in the decision making process re WOT but acknowledges it is the consultant who makes the final decision and is legally responsible for this decision.</p>	<p>Efa feels she is always included in the decision making process re WOT. It is the consultant who makes the final decision and is legally responsible for this decision.</p>	<p>Efa feels she is always included in the decision making process re WOT (she is a senior nurse). It is the consultant who makes the final decision and is legally responsible for this decision.</p>	<p>Nurse involvement in decision making</p> <p>legal responsibility – consultant</p> <p>nurse's knowledge and experience – lends itself to increased involvement in decision making process and autonomy</p>
<p>Q 1.6) Interviewer: How do you feel about extubating a patient during WOT?</p> <p><i>Efa : I personally do not have a problem with extubating the patient during withdrawal of treatment, and in my experience this was done on a patient who had only been with us for</i></p>	<p>Efa is in agreement with extubating a patient during WOT especially if the patient has been in the ICU for a long time – seems more natural to remove</p>	<p>Efa is in agreement with extubating a patient during WOT especially if the patient has been in the ICU for a long time – seems more natural to remove patient's</p>	<p>Nurse appears to be comfortable with terminal extubation but acknowledges not for every patient – where there is noisy dying – give medication to eliminate this</p>	<p>nurse's knowledge and experience</p> <p>experienced nurse comfortable with terminal extubation</p>

<p><i>a few hours but we extubated and removed the ventilator and let her die with no airway support. I think for some of the patients we have been looking after for a long time...I think it is more favourable to remove the airway and extubate them. Just seems more natural without the airway. But this can make intensive care nurses apprehensive as we are taught the golden rule... no airway...no patient...the ABCD principle always starts with supporting and maintaining an airway. It is a strange feeling really when you remove the airway support ...suppose you are removing their lifeline...</i></p>	<p>patient's airway (this means removing the artificial airway)</p> <p>However Efa feels this extubation may make nurses feel apprehensive as it goes against everything they have been taught in the rescue culture of ICU.</p> <p><i>'we are taught the golden rule... no airway...no patient...the ABCD principle always starts with supporting and maintaining an airway.'</i></p> <p><i>'suppose you are removing their lifeline...'</i></p>	<p>airway (this means removing the artificial airway)</p> <p>Efa feels this extubation may make nurses feel apprehensive as it goes against everything they have been taught in the rescue culture of ICU.</p> <p><i>'we are taught the golden rule... no airway...no patient...the ABCD principle always starts with supporting and maintaining an airway.'</i></p> <p><i>'suppose you are removing their lifeline...'</i></p>	<p>symptom because noisy dying may be distressing for family and must be controlled extubation may be viewed as a tension within intensive care ethos and be seen as removing the patient's lifeline and perhaps loss of control during dying</p>	<p>ethos of intensive care practice – ABCDE algorithm</p> <p>Loss of airway = loss of life - noisy dying</p> <p>Clinical environment and rescue/curative culture and care</p> <p>perhaps a dichotomy situation with saving or letting go therapies</p> <p><i>'suppose you are removing their lifeline...'</i></p>
<p>Q 1.7) Interviewer: Would you feel comfortable with a patient who is extubated during WOT?</p> <p><i>Efa : Yes, as long as we have given Hyasine to dry up the oral and bronchial secretions so there is no obstruction to the airway. This may be activated on the LCP as adapted for ICU documentation...we must try to aim for a good death (you know)...</i></p>	<p>Efa answers yes, but adds that medication should be given to dry bronchial secretions which is activated and guided by Liverpool Care of the Dying pathway documentation – so nurse-led practice</p>	<p>Efa answers yes, but adds that medication should be given to dry bronchial secretions which is activated and guided by Liverpool Care of the Dying pathway documentation – so nurse-led practice</p> <p>Underlying problem of</p>	<p>Efa comfortable with extubation but also aware of noisy dying and the implications of not being in control of situation which may distress family and perhaps cause distress to patient and dying process. LCP-ICU only used for medication guidance</p>	<p>nurse's knowledge and experience</p> <p>prevent noisy dying and loss of control of situation</p> <p>nurse-led practice</p>

		obstructed airway leads to noisy breathing	usually as it is a nurse-led practice	controlling dying trajectory
<p>Vignette 2 A 76 year old man with diabetes mellitus and ischaemic heart disease was admitted to the ICU two months ago. His condition has steadily deteriorated and he has established sepsis not responding to antibiotics. He now has gangrene in both legs and hands. The patient is not a candidate for surgery. He is being treated with multiple vasopressor therapies to maintain his cardiovascular status and he is mechanically ventilated on 100% oxygen. His family insist on continuing with all treatment despite being told that his prognosis is poor and that further treatment is futile.....</p> <p>Q 2.1) Interviewer: would you like to discuss this scenario? <i>Efa : I have come across many patients like this... sometimes it is not the entire family who request another 24 hours of treatment, it is usually just one or two members of the family...and particularly the dominant member of the family, the</i></p>	<p>Efa has nursed many patients like this. She goes on to say that sometimes it is 1 or 2 family members who need more time to accept the decision to withdraw treatment – especially if they are the</p>	<p>Efa has experience in nursing many patients similar to the patient described in the scenario. In her experience, she suggests it is the dominant person in the family who acts as the spokesperson on</p>	<p>experience in nursing many patients similar to the patient described in the scenario.</p> <p>the family requests another 24 hours before treatment is withdrawn – they have not come to terms with the</p>	<p>family need time to accept the decision</p> <p>nurse acts as mediator</p> <p>supports family</p>

<p><i>spokesperson...often family dynamics come into play in this type of scenario as well...The nurse usually assesses the family dynamics and is the link to the medical team in order to help the family to resolve these conflicts. To solve this it includes both nurses and doctors otherwise the family will not be content with the decision ...may even feel resentful...and impacts on their ability to grieve...the nurse is the one who sorts out any confusion around futility, care, etc. and informs the doctors of any problematic issues the family may be feeling.. the nurse is part of the family, especially as we get to know the patient and their family so well...spend so much time with them</i></p>	<p>spokesperson for the rest of the family. She mentions family dynamics often emerge during this type of scenario.</p> <p>The nurse plays the role of a mediator between the family and the doctors.</p> <p>Family may even resent the decision to withdraw treatment – their way of coping with the patient's impending dying and death.</p> <p>the nurse is the one who sorts out any confusion around futility, care of patient, dying</p>	<p>behalf of the rest of the family and who requests another 24 hours before treatment is withdrawn. The nurse's role is one of assessor and mediator between the family and the doctors regarding the decision to withdraw treatment, and to prevent conflict.</p> <p>Family may even resent the decision to withdraw treatment – their way of coping with the patient's impending dying and death. Efa sees the nurse as the person who minimises any conflict between family and doctors, and liaises with doctors regarding the family's understanding of WOT.</p> <p>Acceptance of the decision re: WOT will impact on the family's grieving process.</p>	<p>decision yet and need more time – nurse acts as a mediator and information broker but also as a supporter to family.</p>	<p>offers informative explanation</p> <p>family involvement in decision making process important</p> <p>futility of situation</p> <p>nurse feels part of patient's family</p> <p>unique relationship between silent patient, nurse and family</p> <p>spatiality</p> <p>temporality</p>
<p>Q 2.2) Interviewer: How do you feel about his family insisting that all treatment should continue despite his poor prognosis?</p> <p><i>Efa : I can identify with this scenario as I have come across very angry relatives in a similar situation to this and the family were arguing among themselves as well...the family need</i></p>	<p>Efa identifies with this scenario as in her experience she has come across the family's anger towards doctors and within the family circle.</p>	<p>Efa identifies with this scenario as in her experience she has come across the family's anger towards doctors and within the family circle.</p>	<p>previous nursing experience of similar scenarios has taught nurse to identify and rationalise decision made. Nurse able to support family to reach consensus regarding</p>	<p>nurse's knowledge and experience nurse as mediator, supporter and information broker</p>

<p><i>to know everything has been done for the patient and there are no further options available...but even then there is hope.. as far as the family are concerned and in their understanding...we have all this life saving equipment, so why is it not saving the patient's life. The patient in this scenario does not have a good prognosis...he has established gangrene and shutdown... so his quality of life is very poor...and a slow drawn out death if he is left in the present state. The nurse would arrange and initiate an interview between the family and the doctors so that the patient's plan of care could be openly discussed...and also have their questions answered...well some we cannot answer, but at least give them an opportunity to voice their concerns. All patients in ICU have good and bad days. Often the family focus on the good days and not the bad days when it comes to withdrawal of treatment, and the nurse often has to explain the patient's poor prognosis over and over until it sinks in...because the good days keep their hopes alive but they don't want to think of the bad days...so sometimes it is a vicious circle...good and bad, hope and futility...in withdrawal of treatment you do have to help the family to be</i></p>	<p>In an attempt to overcome this anger Efa feels that the family need to know that everything has been done for the patient and that there are no options left. They need to be fully informed and should understand the rationale behind the decision. It is difficult for the family to understand that it is futile to continue treatment when they see the patient being kept alive on the life sustaining therapies.</p> <p>Efa assesses the scenario & comes to the conclusion that the patient is going to die a slow drawn out death if the family are not in agreement with the decision to withdraw treatment.</p> <p>Efa suggests the nurse is the mediator between the family and doctors, and usually initiates a meeting between the two to discuss the way forward – this gives the family a chance to voice their concerns and ask questions.</p>	<p>In an attempt to overcome this anger Efa feels that the family need to know that everything has been done for the patient and that there are no options left. They need to be fully informed and should understand the rationale behind the decision. It is difficult for the family to understand that it is futile to continue treatment when they see the patient being kept alive on the life sustaining therapies.</p> <p>Efa assesses the scenario & comes to the conclusion that the patient is going to die a slow drawn out death if the family are not in agreement with the decision to withdraw treatment.</p> <p>Efa suggests the nurse is the mediator between the family and doctors, and usually initiates a meeting between the two to discuss the way forward – this gives the family a chance to voice their concerns and ask questions.</p>	<p>decision and the futility of further treatment nurse will act as mediator, information broker and support family in this situation</p> <p>Efa suggests the nurse is the mediator between the family and doctors, and usually initiates a meeting between the two to discuss the way forward – this gives the family a chance to voice their concerns and ask questions.</p> <p>difficult for families to conceptualise that there is no further hope for cure in amongst all the advanced technology and accept the futility of further treatment</p>	<p>challenge is caring for patient and simultaneously supporting family (patient care, family support)</p> <p>assisting family to come to terms with decision</p> <p>family struggle with accepting futility of situation –life-sustaining therapies no longer effective</p> <p>nurse advocates as mediator, supporting family, caring for patient and information broker</p> <p>nurse nurtures/supports family regarding acceptance of decision and through withdrawal</p>
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<p><i>focused and realistic. You as a nurse have to be especially focused because the patient's blood results, disease processes, supportive equipment all flash through your mind as you deliver intelligent observation and high quality care. The challenge is maintaining the patient's optimal organ function and support throughout their critical illness.</i></p>				<p>of treatment practice until death</p> <p>nurse's knowledge and experience</p>
<p>Q 2.3) Interviewer: Have you experienced a similar situation?</p> <p><i>Efa: Yes, many times. I have experienced an intense sense of grief when a patient made the decision to forego any further treatment in the ICU and was just on pain relief. This patient had a chronic lung disorder and was on oxygen as she could not go onto the ventilator as we would never get her off again. Her family were with her and so we held her hand and supported her during her dying as we withdrew all her inotropic support. I was very upset with this particular withdrawal of treatment... I had got to know her so well, and her family as well....I was with the family from the beginning of withdrawing treatment to end when the patient died...we all went through the patient's dying...</i></p> <p><i>'suppose you are removing their lifeline...'</i></p>	<p>Efa has experienced many similar situations and goes on to describe her feelings of grief and upset when she nursed a patient with a chronic lung disorder who decided to forego treatment and die instead. She describes how she and the family held the patient's hand and supported the patient during the dying process, and how this upset her immensely.</p>	<p>Efa has experienced several similar situations and felt grief and sadness. She describes how she and the family held the patient's hand and supported the patient during the dying process, and how this upset her immensely.</p> <p>nurse supports and accompanies the patient and patient's family during the patient's dying trajectory</p>	<p>Efa describes her own sense of grief as she accompanied the family through the patient's dying trajectory she mentions how the they held the patient's hand together nurse caring for dying patient whilst simultaneously supporting family during the dying trajectory</p>	<p>nurse also experiences sense of grief</p> <p>nurse's knowledge and experience</p> <p>Patient care</p> <p>Family support</p> <p>therapeutic use of self and touch</p>

<p>Q 2.4) Interviewer: How would you feel in this situation?</p> <p><i>Efa: I would feel sad for the family but ensure a pain free and dignified death for the patient. If this was a younger person, I think it would be harder to accept the decision because of their age. I don't think it affects the outcome of the decision to withdraw but it is much harder to make this decision and then to help the family to understand why... but the patient in this scenario already has co-morbidities like the ischaemic heart disease and diabetes... so he has a poor chance of recovery and poor quality of life anyway. With a younger person they still have a lot to live for..., many have younger children...or if it is unexpected... it is so sad when a young person loses their life. But it does happen and we have to deal with it.</i></p>	<p>In this situation Efa would feel sad for the family but ensure that the patient has a pain free and dignified death. Efa feels the decision to withdraw treatment is somehow easier to accept in older patient yet difficult to accept in younger patients, especially for the nurse to help the family to understand and accept the WOT decision in the younger patient. She continues almost in a self-reassuring manner that the patient in the scenario has co-morbidities and a poor prognosis, so the decision is easier to accept. Efa feels that younger patients have their life ahead of them, may have young children, and the fact that it is always very sad when a young person loses their life. She goes on to say that it does happen in the real world and nurses have to deal with the situation when it arises.</p>	<p>Efa experiences sadness for the family and goes on to say that she will ensure the patient has a pain free and dignified death.</p> <p>Efa feels it is more difficult to accept the WOT decision in younger patients as they have their whole life ahead of them. In her experience regarding WOT and younger patients, she feels it is more difficult to help the family understand and accept the decision to withdraw treatment as well. She feels very sad for the patient and the family anyway with WOT, but especially so with younger patients. However, she goes on to say it happens and is all part of the IC nurse's experiences</p>	<p>the transition from a curative focus of care towards a palliative focus is more readily accepted if the patient has experienced life but more difficult to withdraw treatment from a young patient</p> <p>nurse rationalises decision to withdraw treatment - She continues almost in a self-reassuring manner that the patient in the scenario has co-morbidities and a poor prognosis, so the decision is easier to accept.</p> <p>Efa feels that younger patients have their life ahead of them, may have young children, and the fact that it is always very sad when a young person loses their life. She goes on to say that it does happen in the real world and nurses have to deal with the situation when it arises.</p>	<p>nurse's knowledge and experience</p> <p>Caring for dying patient</p> <p>Supporting family</p> <p>transition from cure to comfort (rescue focus of care moves to palliative care)</p> <p>when situation is futile, cure no longer a reality then aim for good death</p> <p>dying and death in ICU a reality (young and old alike)</p>
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<p>Q 2.5) Interviewer: Can you tell me about it?</p> <p><i>Efa: This type of patient has come to the end of the road as far as intensive care therapies are concerned...there is very little we can do now and it would be futile to continue.</i></p>	<p>Efa feels that the patient in the scenario has run out of intensive care treatment options and that to continue is futile.</p>	<p><i>This type of patient has come to the end of the road as far as intensive care therapies are concerned</i></p> <p><i>...there is very little we can do now and it would be futile to continue.</i></p>	<p>there are no further therapeutic options left to offer this patient</p>	<p>nurse's knowledge and experience futility of situation</p> <p>no further therapies available</p> <p>ethical decision making</p>
<p>Q 2.6) Interviewer: Do you think withdrawal of treatment could be viewed as a failure?</p> <p><i>Efa: Yes, because we work so hard to save the patient, but then we have to withdraw treatment due to his poor prognosis...if we don't then we are just prolonging their life and suffering and ultimately delaying the outcome. Personally when I am involved in withdrawal of treatment, I feel disappointed because you get very close to the patient and their family...if you think of the time and effort invested in saving the patient as well especially in surgical cases...and the continuity with the patient especially if you are doing a string of shifts and looking after the same patient, you get very close to them... withdrawal of treatment is almost a sense of grief for the nurse caring for the patient...often you have been through many a medical crisis with them and pulled</i></p>	<p>Nurse feels that WOT can be viewed as a failure because the staff work so hard to sustain the patient's life but then, due to the poor prognosis, to continue would merely be prolonging the inevitable – so in a way this situation is often a no win situation with regard to curing the patient's illness. In her experience Efa feels disappointed when she is personally involved in the WOT situation because she feels very close to the patient and the family, especially if she has nursed the patient over a period of time and invested so much time and effort in saving and sustaining their life. Efa says this relationship with the patient and family is so intense that during WOT</p>	<p>Efa feels that the patient in the scenario has run out of intensive care treatment options and that to continue is futile.</p> <p>Efa feels that WOT can be viewed as a failure because the staff work so hard to sustain the patient's life but then, due to the poor prognosis, to continue would merely be prolonging the inevitable – so in a way this situation is often a no win situation with regard to curing the patient's illness.</p> <p>In her experience Efa feels disappointed when she is</p>	<p>...all that remains is an empty bed.</p> <p>In her experience Efa feels disappointed when she is personally involved in the WOT situation because she feels very close to the patient and the family, especially if she has nursed the patient over a period of time and invested so much time and effort in saving and sustaining their life. Efa says this relationship with the patient and family is so intense that during WOT the nurse experiences a sense of grief as well – she goes on to say that it is a different type of grief as compared to the family, but could perhaps be referred to 'letting go' after fighting so hard to save the patient. 'WOT is almost a sense of</p>	<p><i>...all you are left with is an empty bed...</i></p> <p>nurse's knowledge and experience</p> <p>nurse experiences sadness for patient and family</p> <p>difficult to let go and withdraw treatment</p> <p>ensure good death</p> <p>nurses feel disappointed especially after rescuing patient from near death and then to allow patient to die following withdrawal of therapies</p>

<p><i>them through...I obviously don't feel the same degree of grief that the family feel but although it is different it remains a sense of grief. When we work with these critically ill patients the nurse devotes a high level of skilled activity and caring to the patient with very high levels of adrenaline and it is a team effort ...working together to save this patient and then the decision is made to withdraw treatment for the right reason, but it is still hard...and afterwards all you are left with is an empty bed...</i></p>	<p>the nurse experiences a sense of grief as well – she goes on to say that it is a different type of grief as compared to the family, but could perhaps be referred to 'letting go' after fighting so hard to save the patient. Efa feels nurses work within a MDT in caring for the critically ill patient and it is a team effort to save the patient, but then the decision is made to withdraw treatment and she agrees that it is the right decision. However after WOT, the nurse is left with an empty bed and no patient.</p>	<p>personally involved in the WOT situation because she feels very close to the patient and the family, especially if she has nursed the patient over a period of time and invested so much time and effort in saving and sustaining their life. Efa says this relationship with the patient and family is so intense that during WOT the nurse experiences a sense of grief as well – she goes on to say that it is a different type of grief as compared to the family, but could perhaps be referred to 'letting go' after fighting so hard to save the patient. Despite the best efforts of the ICU team to save the patient, WOT is indicated and is the right decision</p> <p>for the nurse all that remains is an empty bed after the patient dies .</p>	<p><i>grief for the nurse caring for the patient... often you have been through many a medical crisis with them and pulled them through... I obviously don't feel the same degree of grief that the family feel but although it is different it remains a sense of grief.'</i> <i>'...working together to save this patient and then the decision is made to withdraw treatment for the right reason, but it is still hard... and afterwards all you are left with is an empty bed... '</i></p>	<p>shared journey in ICU milieu - relationship between patient/nurse /family of trust and respect</p> <p>nurse experiences different type of grief as compared to the family</p> <p>difficult to let go after fighting so hard to save the patient</p> <p>decision making process based on ethical principle of futility</p> <p>ICU MDT team</p>
<p>Q 2.7) Interviewer: From my observation, I have noticed that the patient is washed prior to withdrawal of treatment. <i>Efa: I wash the patient before I withdraw treatment and make them presentable to the family... and</i></p>	<p>Efa states that she washes the patient before WOT and makes the patient presentable to the family and washes the patient again after the patient has</p>	<p>Efa feels washing the patient before WOT commences makes the patient more presentable to the family. She also washes the patient after death has occurred.</p>	<p>Efa carries out pre and post mortem care on the patient – the pre mortem care not only makes the patient presentable to the family, but the patient looks cared for. Post mortem</p>	<p>washing of patient- shows family that nurse cares for patient and is respectful as well</p>

<p>anyway there is no time to do this when we are withdrawing treatment. After the patient dies, I will wash the patient again.</p>	died.		care is the final act of caring for the nurse.	pre- and post mortem care important that family know patient receives quality care
<p>Q 2.8) Interviewer: What equipment do you normally withdraw the first during withdrawal of treatment? <i>Efa: The haemofiltration machine, then the inotrope support and eventually the ventilator when the patient dies. Then we remove all the invasive lines etc. when we lay the patient out and prepare them to be taken to the mortuary.</i></p>	<p>Efa says the kidney filtration machine is removed first, followed by the cardiovascular support drugs, and lastly the ventilator is switched off after the patient has died. Whilst conducting the last offices, the nurse removes all invasive lines.</p>	<p>Renal and cardiovascular support are withdrawn, and lastly the respiratory support. This withdrawal of treatment is undoing what is done during the acute, curative resuscitation of the patient when they arrive in the ICU.</p>	<p>Renal and cardiovascular support are withdrawn and lastly the respiratory support. This is the reverse format of the rescue, curative ABCD (airway, breathing, circulation and drugs) during the acute phase of resuscitation when the patient arrived in the ICU! (treatment reversal)</p>	<p>withdrawal viewed as failure</p> <p>time and effort expended to save patient (individual and team)</p> <p>invasive monitoring left in situ during treatment withdrawal – family are familiar to seeing patient this way – feel comfortable with patient who looks like a ‘cyborg’</p>
<p>Q 2.9) Interviewer: In your experience, what was the shortest time from withdrawal of treatment to death? <i>Efa: 10 minutes</i></p>	10 minutes	extremely short period of time	extremely short period of time in this particular case	<p>certain death but unknown time</p> <p>temporality</p>

<p>Q 2.10) Interviewer: And the longest time?</p> <p><i>Efa: I would say about 48 hours, sometimes the patient may have to be transferred to the ward in a side room to die if the bed is needed for another patient in the ICU.</i></p>	<p>following withdrawal of treatment, if the bed is need for another patient, then the dying patient is transferred to a ward</p>	<p>dying patient may be moved to a ward to die – creates tensions as nurse and family have developed this close bond in ICU and now patient will to die among strangers</p>	<p>dying patient may be moved to a ward to die– creates tensions as nurse and family have developed this close bond in ICU and now patient will to die among strangers</p>	<p>different environment for dying with strangers if bed needed – organisational issues and bed resources</p> <p>creates difficulty during the patient's dying trajectory –</p> <p>transfer to ward viewed as bad death which nurses want to avoid.</p>
<p>Q 2.11) Interviewer: I notice the curtains were drawn around the bed once the decision to withdraw treatment has been made. Why do you think this is?</p> <p><i>Efa: This is done as the family arrive...to maintain respect and dignity for the patient and family, to screen them from the rest of the staff and traffic in the ICU...and also to protect the other patients and their families.</i></p>	<p>Efa feels the curtains are closed around the patient's bed as soon as the family arrives as this heralds the commencement of WOT – this is done in an attempt to maintain dignity in dying, as a token of respect for the patient and their family, and to maintain privacy from the rest of the ICU.</p>	<p>Efa feels the curtains are closed around the patient's bed as soon as the family arrive as this heralds the commencement of WOT – this is done in an attempt to maintain dignity in dying, as a token of respect for the patient and their family, and to maintain privacy and protection from the rest of the ICU.</p>	<p>curtains closed from time decision made and only opened fully again after patient has died and body taken to mortuary</p>	<p>closed curtains – symbolise protected space, dignity, restricted entry system, shelters dying patient/ nurse and family from rest of the ICU</p> <p>spatiality</p>

<p>Interviewer: Would you like to discuss a situation where you have withdrawn treatment?</p> <p><i>Efa : One particular patient comes into mind. He was a 40 year old lorry driver who had sustained a head on collision impact on the motorway and was in the ICU for 4 days when it was decided that WOT was impending. He had multi organ failure and multiple contused organs with a severe head injury. However, it (withdrawal of treatment) was not discussed but rather implied because it took a while to get the family involved in the decision making process. Err ...so having done this we then decided to withdraw treatment. This is a gradual process... the family are sort of prepared for it as the days and time go by. So after breaking the news finally to the family we kept him on the ventilator but decreased the oxygen percentage down to room air (21%) from 100%. So there was no extubation, the visual appearance of the patient was the same as what they (the family) had got used to but the oxygen percentage was decreased dramatically. And the family were witness to the care that was being given during the WOT. The withdrawal of treatment is a process...it (withdrawal of treatment) seems to</i></p>	<p>Efa goes on to discuss when she withdrew treatment in a young patient who had sustained severe injuries following a motor vehicle incident and had been in the ICU for 4 days. His prognosis was poor, and the decision to withdraw treatment was initially implied and then discussed as it took a while for the family to accept that WOT was impending. Efa feels the decision to withdraw treatment was not a sudden one, but rather unfolded as the days and time went by. She explains how the news was broken to the family and how the withdrawal of treatment unfolded with the patient still on the ventilator. Interestingly, Efa did not remove any equipment from the patient, but instead chose to leave everything as it was so as to not alter the patient's appearance for the family. She explains that the family were witness to the WOT process and all nursing</p>	<p>Efa discusses how she withdrew treatment in a young patient who had sustained severe injuries following a motor vehicle incident and had been in the ICU for 4 days. His prognosis was poor, and the decision to withdraw treatment was initially implied and then discussed as it took a while for the family to accept that WOT was impending. Efa feels the decision to withdraw treatment was not a sudden one, but rather unfolded as the days and time went by. She explains how the news was broken to the family and how the withdrawal of treatment unfolded with the patient still on the ventilator.</p> <p><i>'withdrawal of treatment is a process... it (WOT) seems to always follow a certain pattern... it occurs in stages... from the discussion regarding WOT, then reviewing that everything has been done for the patient that could be done, to breaking the news, to the actual withdrawal of therapies.'</i></p>	<p>Efa discusses withdrawal of treatment from a young patient who had sustained multiple injuries following a motor vehicle incident and had been in the ICU for 4 days. His prognosis was poor, and the decision to withdraw treatment was initially implied and then discussed as it took a while for the family to accept that WOT was impending. Efa feels the decision to withdraw treatment was not a sudden one, but rather unfolded as the days and time went by. She explains how the news was broken to the family and how the withdrawal of treatment unfolded with the patient still on the ventilator.</p> <p><i>'withdrawal of treatment is a process... it (WOT) seems to always follow a certain pattern... it occurs in stages... from the discussion regarding WOT, then reviewing that everything has been done for the patient that could be done, to breaking the news, to the actual withdrawal of therapies.'</i></p>	<p>nurses' knowledge and experience</p> <p>patient care</p> <p>nurse prepares patient for withdrawal of treatment practice</p> <p>nurse tries to mimic 'natural dying' as withdrawal unfolds</p> <p>nurses' knowledge and experience</p> <p>clinical knowledge and expertise</p> <p>nurse as information broker</p> <p>behaviour pattern of practice of withdrawing treatment may be viewed as an action that leads to a ritual</p>
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<p><i>always follow a certain pattern...it occurs in stages...from the discussion regarding withdrawal of treatment, then reviewing that everything has been done for the patient that could be done, to breaking the news, to the actual withdrawal of therapies. Haemofiltration was the first therapy to be discontinued and this was done prior to withdrawal of treatment, even before the family came in to witness the withdrawal of treatment. Next I withdrew the inotrope support with the family watching... this I did by merely switching the syringe drivers off quietly. It was important to gather all the family around the patient's bed space and being there to support the patient and the family... no easy task because sometimes it is just better to be quiet but be there with them. The monitor above the bed was always left on so this was a focus point for the family as they watched each heart beat... there was still life. I can still visualise the scene ...the closed curtain for privacy, the patient, the family around the bed, the nurse and the monitor...watching and waiting... it is always just a matter of time. Occasionally, some nurses in the ICU would switch the monitor off... to take the focus off the monitor and rather focus on the dying patient. I suppose it</i></p>	<p>care administered during the process. 'withdrawal of treatment is a process... it (WOT) seems to always follow a certain pattern... it occurs in stages... from the discussion regarding WOT, then reviewing that everything has been done for the patient that could be done, to breaking the news, to the actual withdrawal of therapies.'</p> <p>Efa then goes on to explain what she did next – she removed the haemofiltration machine prior to WOT. Whilst the family were present at the bedside, she withdrew the cardiac support drugs quietly by merely switching the syringe drivers off. Efa feels it is important to gather the family around the dying patient's bed space with the nurse being there to support them. She mentions this is no easy task, but sometimes just being there quietly is sufficient. The cardiac monitor above the patient's bed was left on, and was a focus point for the family and the nurse as they</p>	<p><i>'The monitor above the bed was always left on so this was a focus point for the family as they watched each heart beat... there was still life. I can still visualise the scene... the closed curtain for privacy, the patient, the family around the bed, the nurse and the monitor... watching and waiting... it is always just a matter of time.'</i></p> <p>Efa explains the steps she took withdrawing treatment. She feels it is important for the nurse to support the family and the patient within the private bed space afforded by the closed curtains – sometimes the nurse's presence and silence is adequate support. Efa describes the role of the cardiac monitor as a form of clinical gaze for both the family and the nurse as they watch life slowly fade with each heartbeat, but with each beat of the heart their hope is kept alive. Efa says the question regarding the monitor being on or off depends on different nurses' attitudes and family wishes. Efa makes sure that the patient's hands are free to</p>	<p><i>'The monitor above the bed was always left on so this was a focus point for the family as they watched each heart beat... there was still life. I can still visualise the scene... the closed curtain for privacy, the patient, the family around the bed, the nurse and the monitor... watching and waiting... it is always just a matter of time.'</i></p> <p>Efa explains the steps she took withdrawing treatment. She feels it is important for the nurse to support the family and the patient within the private bed space afforded by the closed curtains – sometimes the nurse's presence and silence is adequate support. Monitor reflects life fading, but also hope with each heart beat – clinical gaze (nurse and family).</p> <p><i>'We do it in a certain way which we have learnt or witnessed in our practice from our more experiences</i></p> <p><i>...we have to be organised and be aware of time when we withdraw treatment, because some patients may die within minutes after WOT and yet others take longer.</i></p>	<p>equipment minimised around bed space – allow family access however, invasive lines left in situ – familiar surroundings for family at this fraught time</p> <p>ECG monitor – each heartbeat keeps picture of life alive with hope</p> <p>families wishes respected regarding ECG – symbolic of life and hope</p> <p>Monitor reflects life fading, but also hope with each heart beat – clinical gaze (nurse and family).</p> <p>ritual</p> <p>temporality</p> <p>unknown time,</p>
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<p><i>depends on the situation and the nurse really... but the family were always given the choice in our unit. Removing equipment around the bed could be done fast but quietly, however I left everything (equipment and patient's invasive lines) as it was and rather stayed with the patient and family. Personally, I turn down the lighting around the bed, make sure the patient's arms and hands are available for the family to hold, and I always encourage the family to speak to and touch the patient and hold the patient's hands... to say their goodbyes. We do it in a certain way which we have learnt or witnessed in our practice from our more experienced peers... We have to be organised and be aware of time when we withdraw treatment because some patients may die within minutes after withdrawing treatment and yet others take longer... then there is the issue of the bed being needed for a patient who has gone off big time in the ward. This patient died with his family beside him, with his favourite music playing and his special photographs around him.</i></p>	<p>watched each heart beat signifying life fading away – she can still visualise the scene with the closed curtains, the family, the patient, the nurse and monitor, almost a type of clinical gaze.</p> <p>This patient died with his family beside him, with his favourite music playing and his special photographs around him</p>	<p>enable the family to hold the patient's hands, and she encourages the family to speak to the patient and dims the lighting during WOT. <i>'We do it in a certain way which we have learnt or witnessed in our practice from our seniors or from protocols... We have to be organised and be aware of time when we withdraw treatment, because some patients may die within minutes after WOT and yet others take longer.'</i></p> <p>patient's death appeared and accepted as a good death</p>	<p>patient's death appeared and accepted as a good death</p>	<p>(un)certain death</p> <p>therapeutic use of self and touch</p> <p>supporting family during the dying trajectory</p> <p>good death</p>
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<p>Q 3.1) Interviewer: how did you feel in this situation?</p> <p><i>Efa: I felt err.. I was glad that we as a team had got together and had made a proactive decision. My other feeling was that of the withdrawal process ...that it did not appear to be too abrupt for the family as they clearly had not come to terms with the patient's impending death completely. From a personal point of view, I sometimes still think of this patient and have mixed feelings, but never that it was the wrong decision...perhaps we could have delayed it (the withdrawal of treatment) for a few hours...but then it is merely delaying the inevitable isn't it?... it is hard to let go when you have worked so hard saving the patient and then to just let them slip away ...I see it as a defeat... but appreciate if we are unable to save a patient, then we need to give the patient a dignified death ...but it is difficult in the ICU... because we save patients... well most of the time. Think it is important to make it a friendly environment for the family although they are sad.</i></p>	<p>Efa feels satisfied that this patient died with his family beside him, listening to his favourite music and surrounded by his special photographs.</p> <p>Efa feels part of the team regarding the WOT decision and suggests the decision was proactively taken.</p> <p>She also felt the family had time to come to terms with the decision to withdraw treatment so they were in agreement – this helps the nurses to also move forward with the withdrawal of treatment, and makes it easier to support the family – family support.</p> <p>Nurse reflects back on the scenario and realises it was the correct decision to make although the patient was young.</p>	<p>nurse views this patient's death as a good death with the family in attendance</p> <p>Efa felt the family had time to come to terms with the decision to withdraw treatment so they were in agreement – this helps the nurses to also move forward with the withdrawal of treatment, and makes it easier to support the family</p> <p>nurse reflects on scenario and rationalises decision based on ethical principle of futility</p> <p>it is important to create a conducive environment for dying to occur</p>	<p><i>... it is hard to let go when you have worked so hard saving the patient and then to just let them slip away ...I see it as a defeat... but appreciate if we are unable to save a patient, then we need to give the patient a dignified death ...but it is difficult in the ICU... because we save patients... well most of the time.</i></p> <p>nurse views this patient's death as a good death with the family in attendance</p> <p>Efa felt the family had time to come to terms with the decision to withdraw treatment so they were in agreement – this helps the nurses to also move forward with the withdrawal of treatment, and makes it easier to support the family</p> <p>nurse reflects on scenario and rationalises decision based on ethical principle of futility</p> <p>it is important to create a conducive environment for dying to occur</p>	<p>Withdrawing treatment occurs in stages</p> <p>Closed curtains</p> <p>Supporting family</p> <p>Caring for dying patient</p> <p>nurses' knowledge and experience</p> <p>decision making</p> <p>shared journey to death – unique relationship patient/nurse/family</p> <p>ensure a dignified good death for patient if cure no longer possible</p> <p>withdrawing treatment seems like a defeat/failure</p> <p>conducive environment for dying to occur</p>
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<p>Q 3.2) Interviewer: Did you stay with the patient & family during WOT?</p> <p><i>Efa: Yes, throughout the whole dying process until death.</i></p>	<p>the shared journey to death following treatment withdrawal – patient/nurse/family</p>	<p>the shared journey to death following treatment withdrawal – patient/nurse/family</p>	<p>the shared journey to death following treatment withdrawal – patient/nurse/family</p>	<p>withdrawing treatment occurs in stages</p> <p>closed curtains</p> <p>supporting family</p> <p>caring for dying patient</p> <p>shared journey to death</p>
<p>Q 3.3) Interviewer: Were you included in the decision-making process?</p> <p><i>Efa : Yes, it was the usual practice in the ICU to include the multi-disciplinary team in the decision making process.</i></p>	<p>MDT decision making process – nurse involvement</p>	<p>MDT decision making process – nurse involvement</p>	<p>MDT decision making process – nurse involvement</p>	<p>MDT decision making process</p> <p>nurses involved in process</p>
<p>Q 3.4) Interviewer: Did you discuss with the family after breaking the news if they wanted the ECG monitor on or off?]</p> <p><i>Efa: Yes, and it was their wish to have the monitor left on during withdrawal of treatment. It proved to have a negative effect on the family by requesting the monitor to be left on... although the sound and alarms were off, they would stare at the monitor and watching the</i></p>	<p>Efa felt the wishes of the family to leave the cardiac monitor on during the WOT were respected – according to Efa, this led to a negative experience for the family as they were more focused on the monitor during the</p>	<p>Efa felt the wishes of the family to leave the cardiac monitor on during the WOT were respected – according to Efa, this led to a negative experience for the family as they were more focused on the monitor during the WOT.</p>	<p>nurse suggests where possible the wishes of the family should be respected during the withdrawal process, as each family and situation is different.</p>	<p>nurse's experience and knowledge</p> <p>respecting family wishes</p> <p>visible dying – ECG monitor off</p>

<p><i>heart rate slowing down until it stopped... but I suppose you need to give the family the choice and also take into consideration different people's needs, for instance do they have a learning disability or not... some of our patients' families do have one...</i></p>	<p>WOT. However, Efa acknowledges every family is different and their wishes should always be respected.</p>	<p>However, Efa acknowledges every family is different and their wishes should always be respected.</p>		
<p>Q 3.5) Interviewer: Did you have time for a debriefing session following WOT?</p> <p><i>Efa: Not a formal one, just chatted to my colleagues in the staff tea room and the nurse at the next bed..then after my break I looked after another level 3 patient who had been admitted from the accident and emergency.</i></p>	<p>No formal debriefing conducted, but peer support offered</p> <p>after patient's death, nurse has a break and then back to caring for another level 3 patient and engaged in a curative focus of care</p>	<p>No formal debriefing conducted, but peer support offered</p> <p>after patient's death, nurse has a break and then back to caring for another level 3 patient and engaged in a curative focus of care</p>	<p>No formal debriefing conducted, but peer support offered</p> <p>after patient's death, nurse has a break and then back to caring for another level 3 patient and engaged in a curative focus of care</p>	<p>only informal debriefing, sometimes none at all - no time</p>
<p>Q 3.6) Interviewer: How many WOT's have you conducted in your intensive care experience?</p> <p><i>Efa: Many in my years in ICU, more than 150 at least</i></p>	<p>nurse has acquired experience in withdrawing treatment</p>	<p>nurse has acquired experience in withdrawing treatment</p>	<p>nurse has acquired experience in withdrawing treatment</p>	<p>nurse has experience in the practice of withdrawing treatment</p>

Themes and sub-themes:

1 Decision making

Sub-themes: (consultant, nurse involvement, MDT, family involvement and acceptance); decision to withdraw unfolds with time; family in agreement and understand; family given time to accept decision; breaking the news; senior nurses instigate discussion; doctors and nurses feel withdrawal of treatment may be viewed as a failure; difficult to let go

2 Bed space/curtains/clinical environment

Sub-themes: curtains – privacy, protection and respect; bed space – patient/nurse/family relationship and interaction in this space during dying process, place where dying occurs; clinical environment – equipment and practice

3 Nursing knowledge/experience/role

Sub-themes: nursing care of patient; supporting family; helping family to come to terms with the decision; preparation of patient, family and bed space and clinical environment; mediator; intuition; previous experience of withdrawal practice; creating conducive environment for quiet, pain free and dignified dying to occur; nursing roles during withdrawal process; nurses' own sadness and grief; patient/nurse/family relationship; controlling the withdrawal process

4 The practice of withdrawing treatment/journey to death (shared)

Sub-themes: unfolds as nurses tries to mimic 'natural dying pattern'; controlled to a certain extent, but unknown time to death; the practice of withdrawing follows a pattern; continuity of care for patient; family support; aim for a good death; patient/nurse/family relationship and interaction during withdrawal of treatment

5 Striving for a tranquil, pain free and comfortable dying and good death for the patient

Sub-themes: nursing care of patient; supporting family; helping family to come to terms with the decision; preparation of patient, family and bed space and clinical environment

Appendix J: An example of Ricoeur's analytical framework for the data analysis of observation

An example of a witnessed withdrawal of treatment scenario during observation in the field

	Explanation (what the text is saying)	Naïve understanding [interpretation] – (what I think the text means)	Appropriation – deeper understanding- (what I think it means to wider knowledge and practice)	Theme and sub- themes
(14 th November 2011)				
A fast track handover is conducted by the night duty shift leader to all nursing members of the day shift in the staff tea room. The staff tea room is the location for this fast track handover applicable to both day and night duty nursing staff. Each day duty nurse is allocated a specific patient or maybe two if the patients fulfil the criteria for high dependency as compared to the 1:1 ratio for level 3 intensive care patients. On	Nursing fast track handover – initial handover (brief) so all staff aware of each patient	Brief handover to all members of the nursing team	Fast track handover (handover)	Nursing role
	Staff tea room	Staff tea room in the ICU complex	Staff tea room	Place (in and out of ICU) - spatiality
	Each nurse allocated a patient	Nurse ratio 1:1	Ownership of patient care	nursing role
	Individual handover	Detailed individual handover	Individual comprehensive patient handover	Nursing role

<p>completion of the fast track handover and patient allocation, each nurse then proceeds into the ICU for a detailed individual patient handover which occurs between the night and day nurse at each patient's bed space. After the handover, one nurse says goodbye to the patient and exits the ICU. I learn that this was the night nurse. There is no response from the patient who lies motionless in the bed. The day nurse introduces herself to the patient whilst conducting what appears to be a systematic check of the surrounding machines and equipment to which the patient is attached.</p>	<p>Night nurse says goodbye to patient and day nurse introduces herself. They talk to patient as if the patient is awake and able to respond</p>	<p>Night and day duty nurses – both talk to patient as if the patient is awake and able to respond</p>	<p>Nurses talk to unconscious patient</p>	<p>Nursing role; silent patient- no social death temporality</p>
	<p>Patient lies motionless in bed</p>	<p>Patient unconscious</p>	<p>Silent patient</p>	<p>Silent patient</p>
	<p>Day nurse introduces herself</p>	<p>Day nurse introduces herself</p>	<p>Nurse talks to unconscious patient</p>	<p>Nursing role</p>
	<p>Daily checking of equipment and assessment of patient</p>	<p>Clinical assessment of patient</p>	<p>Clinical environment</p>	<p>Clinical environment and culture</p>
	<p>Obtaining consent for observation - cross reference to methodology</p>	<p>Obtaining consent for observation - cross reference to methodology</p>	<p>Obtaining consent for observation - cross reference to methodology</p>	
	<p>Maintaining</p>	<p>Keeping patient</p>	<p>Keeping patient</p>	

<p>After a brief introduction and explanation with regard to my research and the Participant Information Sheet (PIS), consent for observation is obtained from the nurse. The patient remains motionless in the bed and appears to be suspended by a vast array of invasive lines and tubes which are attached to various machines. The nurse informs me the reason why the patient is lying motionless is because the patient is on continuous infusions of analgesia and sedative drugs to ensure comfort and keep her pain free while attached to the surrounding equipment. Some of the machines are free standing around</p>	<p>patient's comfort and freedom from pain with analgesia and sedation</p>	<p>pain free and comfortable</p>	<p>pain free and comfortable</p>	<p>Nursing role</p>
	<p>Bed space, haemodynamic monitoring, clinical environment, Cultural scene</p>	<p>Bed space, haemodynamic monitoring, clinical environment. Cultural scene</p>	<p>Clinical environment</p> <p>Bed space</p> <p>Cultural scene</p>	<p>Clinical environment and culture</p>
	<p>Researcher location for observation</p> <p>Documentation on large sheet at foot of bed</p>	<p>Researcher location for observation</p> <p>Documentation on large sheet at foot of bed</p>	<p>Researcher position during observation - centrality</p> <p>Documentation</p>	<p>Nursing role; clinical environment and culture</p>

<p>the bed and some are suspended and secured on a sophisticated apparatus system which resembles an octopus behind the patient's bed. A computerised monitor is also suspended to the left of the patient above the head of the bed. I position myself at the nurses' station for my observation in order to ensure a bird's eye view of the specific bed space. The nurse is immersed in documenting something on a very large sheet of paper and busily works through numerous sheets of paperwork on a large table at the foot of the bed. She then draws the curtain around the patient's bed space and I hear her</p>	Closed curtains to maintain privacy	Closed curtains to maintain privacy	Closed curtains	Bed space and curtains
	nurse talks to patient as if patient able to respond	Nurse talks to patient as if patient able to respond	Nurse/patient relationship Silent patient	Nursing role
	Patient assessment and clinical environment	Patient assessment and clinical environment	Nursing practice, clinical environment	Nursing practice, clinical environment
	Curtain open	Curtain open	Curtain open	bed space and curtains
	Documentation and nursing practice	Documentation and nursing practice	Documentation and nursing practice	Nursing role
	Clinical environment	Clinical environment	Clinical environment	Clinical environment and culture

<p>talking to the patient as if the patient were conscious and able to respond. She discusses what she is about to do with regards to assessing her physically and generally conducts a casual conversation about the weather outside, time of day and the date. The curtain surrounding the bed space is now drawn back, and the nurse is once again writing on the large chart at the foot of the bed and shuffling through various other pieces of paper.</p> <p>The nurse then administers what appears to be intravenous medications, takes a sample of blood which she inserts into a</p>	<p>Bed space</p> <p>Nurse joined by more people</p> <p>Clinical environment, cultural scene – pre-decision making</p> <p>ICU secretary is my key informant</p> <p>Secretary informs me of each person's job description and role in the team</p> <p>Staff clothed in scrubs except for consultant</p>	<p>Bed space</p> <p>Nurse joined by intensive care MDT</p> <p>Clinical environment, cultural scene – pre-decision making</p> <p>ICU secretary is my key informant</p> <p>Secretary informs me of each person's job description and role in the team</p> <p>Clothing attire</p>	<p>Bed space, MDT, ICU doctors round</p> <p>Clinical environment, cultural scene – pre-decision making</p> <p>Key informant</p> <p>ICU MDT members</p> <p>Clothing attire – scrubs</p>	<p>Bed space and curtains; patient;</p> <p>clinical environment and culture; nursing role</p> <p>Key informant</p> <p>Decision making and withdrawal of treatment</p> <p>Clothing attire</p>
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<p>machine, and after a minute the machine prints a piece of paper which she reads and documents on the patient's chart. She walks over to the nurses' station and from a computer retrieves another A4 size printed piece of paper, which I am informed is the patient's blood results, and appears to be collating charts and other paperwork at the foot of the patient's bed. Soon thereafter, several people approach the patient's bed area and greet the nurse. They are all clothed in the blue attire commonly called 'scrubs', with the exception of a male who is dressed in ordinary clothes. The ICU</p>	<p>Clinical information</p> <p>Level 3 patient profile</p>	<p>Clinical information</p> <p>Level 3 patient profile</p>	<p>Clinical information</p> <p>Level 3 patient profile</p>	<p>culture</p> <p>Clinical environment and culture; nursing role</p>
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<p>secretary eagerly informs me that this is the intensive care multi-disciplinary team who conduct a morning round every day to assess each patient in the ICU. The secretary points out each member of the team and describes their role and responsibility, and informs me that the consultant in charge of the ICU for the day is not dressed in scrubs. Present at the bedside are the nursing shift leader accompanied by the anaesthetic consultant, two anaesthetic registrars, the nurse looking after the patient and the intensive care pharmacist (who is carrying a rather thick</p>	<p>Pre-decision making</p>	<p>Pre-decision making</p>	<p>Pre-decision making</p>	<p>Decision making</p>
	<p>Curtains closed</p>	<p>Curtains closed</p>	<p>Curtains closed</p>	<p>Bed space and curtains</p>

<p>book under her arm).</p> <p>[The intensive care nursing and medical personnel are apparently aware that I am a researcher conducting a study pertinent to withdrawal of treatment, according to the ICU secretary. The shift leader has informed them prior to the morning round. They appear to be comfortable with the idea of having a researcher in their midst.]</p> <p>I am later informed by the nurse that the patient is a 39 year old female who has been treated in the ICU for the past two weeks with a confirmed diagnosis of sepsis and multi-organ failure. The patient has a history of alcohol abuse from an early age with numerous episodes of pancreatitis necessitating several hospital admissions in the past which have all led to ICU admission.</p>	<p>Explanation of clinical environment</p> <p>Curtains closed</p> <p>People talking behind curtains</p> <p>Discussion now outside closed curtains at foot of patient's bed space</p> <p>Actual decision making</p>	<p>Explanation of clinical environment</p> <p>Curtains closed</p> <p>People talking behind curtains</p> <p>Discussion now outside closed curtains at foot of patient's bed space</p> <p>Actual decision making</p>	<p>Explanation of clinical environment</p> <p>Curtains closed</p> <p>People talking behind curtains</p> <p>Discussion now outside closed curtains at foot of patient's bed space</p> <p>Actual decision making</p>	<p>Clinical environment</p> <p>Bed space and curtains</p> <p>Bed space and curtains</p> <p>Decision making</p>
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<p>Despite maximum medical therapy and technological supportive therapy for multiple organ failure, the patient's condition has steadily deteriorated rather than improving, and has not responded to the supportive therapy administered. The secretary explains that each patient's vital signs are apparent on the central computer at the nurses' station.</p> <p>Memo: I am impressed by her knowledge and insight as she explains what each continuous tracing and value signifies, and appears to have insight as to what is normal and what is abnormal. These rows of luminous green numerical values and tracings for each patient cascade across the monitor screen highlighting a life which exists beyond this myriad of wires, tubes and machinery attached to the patient. The identical tracings and values are reflected on the monitor above the patient's bed</p>	<p>People leave area and curtain slightly drawn back – decision made to withdraw treatment</p> <p>Decision documented by consultant – people move to next bed to continue ICU round</p>	<p>People leave area and curtain slightly drawn back – decision made to withdraw treatment</p> <p>Decision documented by consultant – people move to next bed to continue ICU round</p>	<p>People exit bed space, curtain slightly drawn back</p> <p>Decision made to withdraw treatment</p> <p>Decision documented, team move to next bed to continue ICU round</p>	<p>Bed space and curtains; decision making</p> <p>Decision making</p>
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space.				
The curtain is drawn around the patient's bed space which the nurse tells me is to maintain patient privacy, especially when the staff are working with the patient or assessing the patient.	Legal responsibility to withdraw treatment lies with consultant in UK	Legal responsibility to withdraw treatment lies with consultant in UK	Legal responsibility to withdraw treatment lies with consultant in UK	Decision making
Memo: A constant hissing and clicking sound is audible from the patient's bed space.	Decision made on ethical principle of futility	Decision made on ethical principle of futility	Futility	Decision making
The nurse informs me that these sounds are coming from the mechanical ventilator and the renal haemofiltration machine.	Change in nurse's demeanour	Change in nurse's demeanour	Change in nurse's demeanour – sadness	Nursing role
The curtain remains drawn around the patient's bed space and a flurry of voices may be heard from behind the curtain now. This is	Decision made to withdraw, nurse now contacts family to come in for a meeting with consultant to discuss the patient's status and breaking the bad news	Decision made to withdraw, nurse now contacts family to come in for a meeting with consultant to discuss the patient's status and breaking the bad news	Decision made to withdraw Nurse contacts family to meet with consultant to discuss the patient's status Breaking the news	Decision making; nursing role; family involvement
	Family involvement	Family involvement	Family involvement	

<p>followed by a discussion which takes place at the foot of the patient's bed but outside the curtain, involving all the staff present.</p> <p>Memo: The nurse caring for this patient and the ICU secretary are my key informants on this particular day of observation.</p> <p>I later learn from the nurse that the discussion which occurred at the foot of the bed involved the team discussing the ethical and moral issues, physiological indicators, current clinical profile and prognosis pertinent to the patient and the rationale for not escalating or continuing further treatment. Although the discussion</p>				
	Nurse prepares the bed space and patient for withdrawal of treatment	Nurse prepares the bed space and patient for withdrawal of treatment	Preparation of patient and bed space for withdrawal	Bed space and curtains; nursing role
	Handing over care of patient to nurse at adjacent bed	Continuity of care while nurse on break	Continuity of care	Nursing role temporality
	Nurse returns from break, joined by another nurse	Nurse returns from break Joined by another nurse and they prepare	Nurse returns to ICU	Nursing role; bed space and curtains

<p>occurs in low voice tones, it is still audible. It is apparent that the intensive care personnel are actively contributing towards and are engaged in the ensuing debate and discussion. The team then enter the patient's bed space again behind the closed curtain, but further discussion is no longer audible. The team emerge from behind the closed curtain, which is drawn back slightly by the nurse caring for the patient, and the consultant busily writes on the documents at the foot of the bed. The morning intensive care round continues as the team then make their way to the next bed space to review the next</p>	<p>Curtains closed</p> <p>Both nurses are talking to patient</p> <p>Soiled linen removed from behind the closed curtains</p> <p>Two chairs placed alongside the bed area</p> <p>Nurse takes documentation to nurses' central station in the middle of the ICU</p>	<p>the patient for the withdrawal and talk to patient</p> <p>Prepare bed space for family</p> <p>Nurse removes documentation from patient's bed space</p>	<p>Closed curtains</p> <p>Joined by another nurse</p> <p>Patient and bed space prepared for withdrawal</p> <p>Both nurses talk to silent patient</p>	<p>Bed space and curtains</p> <p>Family involvement</p>
	<p>Curtains closed</p>	<p>Curtains closed</p>	<p>Curtains closed</p>	
	<p>Family arrive in ICU</p>	<p>Family arrive in ICU</p>	<p>Family arrive in ICU</p>	

<p>patient. The nurse informs me, after the team have moved to the next patient's bed space, that the consultant has documented his decision to withdraw treatment in this patient today. She mentions that the consultant is responsible for making the final decision with regard to withdrawal of treatment and that it is legally binding to document this decision clearly on the patient's charts. The rationale behind this decision, made in agreement within the multi-disciplinary intensive care team, is based on the ethical principle of futility. She then goes about her work in a quiet</p>	<p>Nurse greets family</p> <p>Leaves family with patient and fetches consultant</p> <p>They accompany the family out of the ICU to a small room still within the ICU complex to break the news regarding withdrawing treatment</p> <p>Consultant, family and nurse return to ICU and consultant leaves nurse with family at patient's bed space and joins the ICU round again</p>	<p>Nurse greets family</p> <p>Leaves family with patient and fetches consultant</p> <p>They accompany the family out of the ICU to a small room still within the ICU complex to break the news regarding withdrawing treatment</p> <p>Consultant, family and nurse return to ICU</p> <p>consultant leaves nurse with family at patient's bed</p>	<p>Nurse greets family</p> <p>Fetches consultant</p> <p>They accompany the family out of the ICU to a small room still within the ICU complex to break the news regarding withdrawing treatment</p> <p>Consultant, family and nurse return to ICU</p> <p>Consultant leaves nurse with family at patient's bed space</p>	<p>Nursing role; decision making; family involvement</p> <p>Start of withdrawal of treatment</p> <p>Nursing role</p>
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<p>manner, but appears rather subdued and has a sombre look on her face. The decision has been made and the nurse informs me that she will now notify the patient's family to come in so that the consultant may break the news to them. Next she will prepare the patient and the bed space (i.e. remove all unnecessary equipment from the bed area) for the impending withdrawal of treatment.</p> <p>Memo: In contrast to the hive of nursing and medical activity prior to the morning round, there appears now to be a sudden lull and quietness surrounding the patient's bed space, after the team continue with the intensive care morning round. The mood throughout the ICU appears sombre; even the ICU secretary is less talkative. It is somehow apparent that the personnel are aware of the impending withdrawal of treatment from this</p>	<p>audible crying apparent behind the closed curtains</p> <p>Nurse stays with family behind the curtains</p>	<p>space</p> <p>Audible crying apparent behind the closed curtains</p> <p>Nurse stays with family behind the curtains</p>	<p>Audible crying behind the curtains</p> <p>Family support</p>	<p>Nursing role; family support/involvement</p> <p>Nursing role; family support</p>
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<p>particular patient.</p> <p>The nurse walks over to the nurses' station and conducts a telephonic conversation with the family of the patient, informing them that their presence is requested in the ICU. She returns to the patient's bed space and spends some time talking to the nurse in the adjacent bed space.</p> <p>Memo: The secretary tells me she is handing the patient over and the other nurse 'will keep an eye' on her patient while she has her morning break.</p> <p>The nurse then exits the unit for her morning break. After a while, she returns from her break and closes the curtain, with another nurse in attendance. Their voices may be heard behind</p>	<p>Cultural and clinical environment</p> <p>Normal flow of traffic in ICU with parent teams assessing patients and routine daily deliveries</p> <p>But noise level is quieter – change in environment</p>	<p>Cultural and clinical environment</p> <p>Normal flow of traffic in ICU with medical and surgical teams assessing patients and routine daily deliveries</p> <p>But noise level is quieter – change in environment</p>	<p>Cultural and clinical environment</p> <p>Normal flow of traffic in ICU</p> <p>Change in environment noise level</p>	<p>Clinical environment and culture</p> <p>Clinical environment and culture</p> <p>Clinical environment and culture</p> <p>Nursing role; family support; bed space</p>
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<p>the closed curtain and it appears that they are explaining things to the patient. The second nurse exits the bed space carrying what appears to be soiled bed linen. The patient's nurse emerges several times after this, collects two blue plastic chairs and places them at the bed space behind the curtain, and collates some paperwork from the nurses' station which she takes with her to the patient's bed space.</p> <p>The nurse informs me that the curtain surrounding the bed space will remain closed throughout the procedure of withdrawal of treatment.</p> <p>After about an hour, the</p>	<p>Grieving family</p> <p>Nurse supporting family</p> <p>Nurse withdrawing treatment</p> <p>Nurse talking softly, change in ventilator sound, crying louder, then silence</p> <p>Nurse and family leave the ICU from behind the closed curtains</p> <p>Doctor certifies patient's death</p>	<p>Grieving family</p> <p>Nurse supporting family</p> <p>Nurse withdrawing treatment</p> <p>Nurse talking softly, change in ventilator sound, crying louder, then silence</p> <p>Nurse and family leave the ICU from behind the closed curtains</p> <p>Formal notification of</p>	<p>Supporting family</p> <p>Nurse withdrawing treatment</p> <p>Nurse talking softly, ventilator sound stops, crying louder, then silence</p> <p>Nurse and family leave the ICU from behind the closed curtains</p> <p>Patient's death confirmed formally</p>	<p>and curtains</p> <p>Nursing role; family support; bed space and curtains</p> <p>Nursing role; family support; bed space and curtains</p> <p>decision making post withdrawal of treatment</p>
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<p>front door buzzer of the ICU heralds the arrival of the patient's family.</p> <p>Memo: The ICU secretary goes over to the nurse behind the curtain and quietly announces that the relatives of the patient have arrived.</p> <p>The family (a middle aged man and woman) hurriedly enter the ICU and appear nervous.</p> <p>They are greeted by the nurse at the patient's bed space. She speaks to them in a caring and friendly manner, ushering them into the bed space behind the closed curtain. After a while, the nurse emerges and disappears for a few minutes and on her return is followed by the consultant. Together they usher the family out</p>	<p>Family do not return to ICU</p> <p>Curtains opened after last offices conducted and patient's body taken to mortuary</p> <p>Nurse takes a break in ICU tea room</p>	<p>patient's death</p> <p>Family do not return to ICU</p> <p>Curtains opened after last offices conducted and patient's body taken to mortuary</p> <p>Nurse takes a break in ICU tea room</p>	<p>Family do not return to ICU</p> <p>Patient given last offices</p> <p>Taken to mortuary</p> <p>Curtains opened</p> <p>Nurse takes a break in ICU tea room</p> <p>Only time nurse has to work through her feelings after withdrawing treatment</p>	<p>Bed space and curtains</p> <p>Nursing role; bed space and curtains</p> <p>Nursing role; clinical environment and culture</p>
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<p>of the ICU.</p> <p>Memo: The ICU secretary informs me they have been taken to the private counselling room within the ICU complex where the news is broken regarding the decision to withdraw treatment and the patient's impending death is discussed.</p> <p>The consultant, the nurse and the family return to the patient bed space once again where the consultant proceeds to join the multi-disciplinary team on the ICU round. The female relative is supported by the nurse who links her arm into the woman's arm. They are behind the closed curtain again. Soft crying and muffled voices are audible from the patient's bed space.</p> <p>Memo: This scenario of soft crying and muffled voices continues for the next hour.</p>	<p>Nurse explains her role in caring for patient and supporting the family during the withdrawal process</p>	<p>Nurse explains her role in caring for patient and supporting the family during the withdrawal process</p>	<p>Nurse's role – caring for patient and supporting family during withdrawal process</p>	<p>Nursing role; decision making and withdrawal of treatment</p>
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<p>No one leaves the bed space during this time.</p> <p>The nurse stays with the family at the patient's bed side throughout this time behind the closed curtain. Only the hiss of the ventilator is audible.</p> <p>Memo: I glance at the monitor screen at the nurses' station and notice that the patient's numerical values have decreased, especially her heart rate.</p> <p>The rest of the ICU personnel continue with what appears to be their normal daily activities with the occasional bonging of alarms, telephones ringing at the nurses' station, and the ICU entrance buzzer heralding the arrival of internal and external visitors. Throughout the withdrawal of treatment,</p>				
	<p>Work carries on as usual – nurse back in the ICU and caring for critically ill patients again</p>	<p>Work carries on as usual – nurse back in the ICU and caring for critically ill patients again</p>	<p>Nurse back in ICU</p> <p>Caring for another patient now</p> <p>Curtains closed</p>	<p>Nursing role; bed space and curtains; clinical environment</p>

<p>there is a steady flow of people entering and leaving the ICU, some with stethoscopes strung around their necks but all dressed in plain clothes. Several trolleys are wheeled into the ICU, some visibly containing heavily laden linen stacked high and others with a multitude of boxes varying in size which I am told is pharmacy and general stock replacement. However, the noise level throughout the ICU appears quieter. Behind the closed curtain, silence reigns at the patient's bed space and very little movement is apparent. The family are heard to be sobbing and voices talking in a low tone are now barely</p>				
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<p>audible from behind the curtain as the nurse remains with the family.</p> <p>Memo: I notice that as the patient's heart rate slows down on the ECG monitor, the louder the sobbing behind the curtains becomes.</p> <p>The nurse's voice is audible at the start of the withdrawal of treatment, but her tone now appears softer. Suddenly the hissing noise stops, the crying is now audibly louder at the bedside for a short period of time and then there is silence. A few minutes later the sobbing family emerge from behind the closed curtain, followed closely by the nurse and together they exit the ICU. The nurse returns to the ICU after about 15</p>				
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<p>minutes and notifies the anaesthetic registrar of the patient's death. He then enters the patient's bed space to certify the patient's death. This is later confirmed by the nurse when I enquire about it. The family of the deceased patient do not come back into the ICU.</p> <p>The curtain is only opened again after the nurse and another nurse conduct what I later learn was the last offices. Soon thereafter two men pushing a silver trolley with a hood on it enter the ICU and the bed space behind the closed curtains. They leave and exit the ICU with the trolley after a few minutes. The nurse informs me the</p>				
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<p>men are hospital porters who are taking the dead patient to the hospital mortuary. The nurse takes a break for 30 minutes in the staff tea room. I join the nurse in the staff tea room for my break where she remarks:</p> <p><i>...‘well, we did everything in our power to sustain the patient’s life’. ‘But unfortunately it was not good enough! ... anyway at least we could ensure a dignified and pain free death for the patient!’ ‘It is just so hard for the relatives you know ... knowing there is nothing more we can do for the patient’. ‘I feel really sad when we withdraw treatment and sometimes it is difficult to not cry when you are with the relatives and everyone involved with the care of the patient feels a sense of helplessness and loss’.</i></p> <p>The nurse explains to me her role during withdrawal of treatment and patient’s journey to</p>				
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<p>death. She mentions her remit involves supporting the family and to ensure the patient is comfortable, pain free and has a dignified death. Once the consultant has confirmed and documented the withdrawal of treatment, the nurse caring for the patient prepares for and conducts the withdrawal of treatment. We sip our coffee in silence, while I write my notes and the nurse pages blankly through a magazine, occasionally directing her attention to the plasma television screen on the wall. I ask her if she would like to talk about her feelings regarding the withdrawal of treatment, but she</p>				
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<p>tearfully declines saying:</p> <p><i>...‘aw, it is just nice to be here (in the tea room) away from it all for a while, I know you know what it is like, sometimes it helps just to know someone understands what we intensive care nurses go through’.</i></p> <p>The nurse enters the unit again from her break and helps another nurse with a new admission, a patient who has arrived from recovery room. She disappears behind the curtain drawn behind the patient’s bed space.</p> <p><i>Researcher (reflexive self): From the time the multi-disciplinary team leave the patient’s bed area, the following 2 hours and 40 minutes of events appear to be time-lapsed in an unknown, yet shared transitional journey. This patient’s journey has unfolded and moved from a curative, rescue culture to a palliative comfort perspective – from a life event which encompasses technological and advanced supportive measures to sustain life at all costs, to attempting to</i></p>				
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<p><i>mimic natural dying in (un)certain death and unknown time. A patient has died, a family and a nurse are bereaved and life goes on in the 'hidden' world of the ICU.</i></p> <p><i>I almost feel as if I have accompanied this nurse in the withdrawal process and for a split second I recall the emptiness I often felt when I was a practitioner and sat in a tearoom after withdrawing treatment in a critically ill patient. As I glance back to reading my field notes, my researcher role soon returns.</i></p>				
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Themes and sub-themes:

- 1 Access to ICU (entering and exiting ICU complex) (In – bed space, curtains; out – staff tearoom, counselling room)

Sub-themes: Occurs throughout the entire withdrawal of treatment process (nurse, family, doctors and others)

- 2 Family

Sub-themes: Family involvement, family support, breaking the news

- 3 Nursing role

Sub-themes: Change in nurse's demeanour (sadness), nurse withdrawing treatment, handover, talking to patient, nursing experience, nursing practice, caring for the patient, supporting the family, nurse's role of keeping patient pain free and comfortable, ownership of patient

- 4 Patient

Sub-themes: Silent patient, ICU doctors' round, withdrawal of treatment, patient's death, patient profile

- 5 Decision making

Sub-themes: Decision making, consultant, MDT

6 Bed space and curtains

Sub-themes: Bed space and curtains (traffic light sanctioning, spatiality, entry and exit, private or public)

7 Clinical environment and cultural scene

Sub-themes: Key informants, clinical environment, cultural scene, documentation

Appendix K: Glossary of terms used for observations in the field

(This section was included at the start of each withdrawal of treatment event witnessed.)

Fast track handover – the nursing shift leader gives a summarised overview of each patient to all the day duty staff at the start of the shift. The same occurs with day to night handover.

Detailed individual handover – this is a comprehensive individual patient handover between a night duty nurse who has cared for the patient during the past 12 hours and a day duty nurse who will take over the care of the patient for the next 12 hours. It is a systematic trajectory and discussion of the holistic treatment and care plans relevant to the patient, and includes all medications, intake/output management, invasive technological support, the patient's vital parameters and response to therapy. The patient's bodily systems are discussed holistically (e.g. cardiovascular, respiratory, renal, gastro-intestinal, endocrine, neurological, skin and integral, hepatic systems) and incorporate all investigations, blood results, etc. relevant to the particular patient. The nurse staff ratio for level 3 patients in ICU is 1:1.

Anaesthetic registrar – is a qualified specialist doctor, with a minimum of 6 years' clinical experience, who has successfully completed the MRCP examinations and chosen the anaesthetic discipline of medicine.

Anaesthetic consultant – is a qualified specialist doctor, with a minimum of 8 years' clinical experience, who has successfully completed the MRCP examinations and Academic Clinical Fellowship, and is specialised in anaesthesia.

Nursing shift leader (also known as charge nurse) – is a qualified nurse who has an additional qualification in intensive care nursing science, a minimum of 5-8 years of intensive care experience and is Band 7 status.

Intensive care pharmacist – is a qualified senior pharmacist allocated to the ICU.

Priority alarms – at each patient's bed space, the computerised monitor functions to cascade the different patient parameters in luminous green colour, with different priority alarms which indicate a change in the patient's parameters. Each alarm has a low and high setting. These priority alarms are distinguishable by different sounds and indicate a change in the patient's parameters.

The **monitor** at each patient's bed space and at the nurses' station reflects different tracings, each tracing indicating a specific numerical value for a specific parameter:

- the top tracing is the ECG (electrocardiograph) trace which is indicative of the patient's heart rate
- the mean arterial pressure (MAP) trace is indicative of the blood pressure
- the central venous pressure trace (CVP) is indicative of the pressure in the right atrium and circulating fluid volume

- the respiratory rate is indicative of the patient's breathing rate
- the oxygen saturation trace is indicative of the percentage of oxygen circulating in the bloodstream and is an indication of lung function.

Appendix L: Diagram of the patient's critical care journey

